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# In the Supreme Court of the United States

OCTOBER TERM, 1984

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MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

*v.*

AMERICAN HOSPITAL ASSOCIATION, ET AL.

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## PETITION FOR A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

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CHARLES FRIED
*Acting Solicitor General*

WM. BRADFORD REYNOLDS
*Assistant Attorney General*

CHARLES J. COOPER
*Deputy Assistant Attorney General*

EDWIN S. KNEEDLER
*Assistant to the Solicitor General*

WALTER W. BARNETT
MARK L. GROSS
*Attorneys*

*Department of Justice*
*Washington, D.C. 20530*
*(202) 633-2217*

10 pp

## QUESTION PRESENTED

Whether Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, prohibits a hospital program receiving federal financial assistance from withholding nourishment or medically indicated treatment from a handicapped child, or otherwise discriminating against the child, solely because of his handicap.

## PARTIES TO THE PROCEEDING

The petitioner is Margaret M. Heckler, the Secretary of Health and Human Services.

The respondents are the plaintiffs in two suits filed in the district court that were consolidated in that court and in the court of appeals. The plaintiffs in *American Hospital Association, et al.* v. *Heckler* are the American Hospital Association, the Hospital Association of New York State, and Strong Memorial Hospital of the University of Rochester. The plaintiffs in *American Medical Association, et al.* v. *Heckler* are the American Medical Association, the American Hospital Association, the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Acadamy of Family Physicians, and Drs. Hubert A. Ritter, Peter A. M. Auld, Rita Gilman Harper, and Roy Howard Petrie.

## TABLE OF CONTENTS


| | Page |
|---|---|
| Opinions below | 1 |
| Jurisdiction | 1 |
| Statute and regulations involved | 2 |
| Statement | 2 |
| Reasons for granting the petition | 11 |
| Conclusion | 28 |
| Appendix A | 1a |
| Appendix B | 4a |
| Appendix C | 48a |
| Appendix D | 50a |
| Appendix E | 53a |


## TABLE OF AUTHORITIES

Cases:


*Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985) ..18, 19, 21, 22, 24

*American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395 ..... 2-3, 7

*American Tobacco Co.* v. *Patterson*, 456 U.S. 63.... 12

*Community Television* v. *Gottfried*, 459 U.S. 498.. 18, 19, 23

*Consolidated Rail Corp.* v. *Darrone*, No. 82-862 (Feb. 28, 1984) .....12, 16, 17, 18, 19

*General Electric Co.* v. *Gilbert*, 429 U.S. 125..... 24

*Grove City College* v. *Bell*, No. 82-792 (Feb. 28, 1984) ..... 16, 21

*Guardians Ass'n* v. *Civil Service Comm'n*, 463 U.S. 582 ..... 23

*Infant Doe, In re*, No. GU 8204-004A (Apr. 12, 1982), writ of mandamus dismissed *sub nom. State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (Ind. Cir. Ct. May 27, 1982) ..... 20

Cases—Continued: Page

*Jefferson County Pharmaceutical Ass'n* v. *Abbott Laboratories*, 460 U.S. 150 ..... 21
*Kosak* v. *United States*, No. 82-618 (Mar. 21, 1984) ..... 12
*Lau* v. *Nichols*, 414 U.S. 563 ..... 23
*North Haven Board of Education* v. *Bell*, 456 U.S. 512 ..... 13, 16, 21
*Southeastern Community College* v. *Davis*, 442 U.S. 397 ..... 10, 14, 15, 18, 21, 22, 24
*Udall* v. *Tallman*, 380 U.S. 1 ..... 23-24
*United States* v. *Baylor University Medical Center*, 736 F.2d 1039, cert. denied, No. 84-525 (Jan. 21, 1985) ..... 16
*United States* v. *University Hospital of the State University of New York at Stony Brook*, 575 F. Supp. 607 ..... 9, 16
*United States* v. *University Hospital of the State University of New York at Stony Brook*, 729 F.2d 144 ..... *passim*
*United States* v. *Weber Aircraft Corp.*, No. 82-1616 (Mar. 20, 1984) ..... 21
*Youngberg* v. *Romeo*, 457 U.S. 307 ..... 23

Statutes and regulations:

Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 *et seq.* ..... 26
§ 122, 98 Stat. 1752 ..... 27
§ 127(a), 98 Stat. 1754 ..... 27
Child Abuse Prevention and Treatment Act, 42 U.S.C. 5101 *et seq.* ..... 26
Civil Rights Act of 1964, Tit. VI, 42 U.S.C. 2000d *et seq.* ..... 10, 19, 28
Rehabilitation Act of 1973 § 504, 29 U.S.C. 794 ..... *passim*
29 U.S.C. 706(7)(B) ..... 13, 18
29 U.S.C. 706(7)(B)(iii) ..... 14
42 U.S.C. 291 *et seq.* ..... 16
42 U.S.C. 1395 *et seq.* ..... 16
42 U.S.C. 1396 *et seq.* ..... 16

Statutes and regulations—Continued: Page

45 C.F.R.:
Pt. 80:
Section 80.6 (c) ..... 8
Pt. 84:
Section 84.3 (h) ..... 17
Section 84.3 (j) (2) (i) ..... 14
Section 84.3 (j) (2) (ii) ..... 14
Section 84.3 (k) (4) ..... 15
Section 84.4 ..... 22
Section 84.44 (b) ..... 7
Section 84.52 ..... 17, 22
Section 84.53 ..... 22
Section 84.55 ..... 2, 16
Section 84.55 (a) ..... 5
Section 84.55 (c) ..... 6, 27
Section 84.55 (d) ..... 6
Section 84.55 (e) ..... 6
Section 84.55 (f) ..... 5
Section 84.55 (f) (1) (iii) ..... 6
Section 84.55 (f) (2) ..... 5
Section 84.55 (f) (3) (i) ..... 5
Section 84.55 (f) (3) (ii) ..... 5
Section 84.61 ..... 8
App. A ..... 5
para. 1 ..... 16
para. 2 ..... 16
para. 5 ..... 15
para. 36 ..... 22
App. C ..... 2, 16
para. (a) (1)-(4) ..... 4
para. (a) (3) ..... 19
para. (a) (5) (i) ..... 11
para. (a) (5) (i)-(iv) ..... 4
para. (b) ..... 7

Miscellaneous:
118 Cong. Rec. (1972):
p. 30681 ..... 18
p. 32310 ..... 18

Miscellaneous—Continued: Page

119 Cong. Rec. 5862 (1973) ..... 18
130 Cong. Rec. S11699 (daily ed. Sept. 21, 1984).. 27
41 Fed. Reg. (1976):
p. 29548 ..... 23
p. 29559 ..... 23
42 Fed. Reg. 22677 (1977) ..... 13
47 Fed. Reg. 26027 (1982) ..... 3
48 Fed. Reg. (1983):
p. 9630 ..... 3
p. 30846 ..... 3
p. 30847 ..... 20, 24, 26
p. 30848 ..... 24, 26
49 Fed. Reg. (1984):
p. 1622 ..... 3, 5
pp. 1622-1623 ..... 2, 3
pp. 1623-1625 ..... 5
p. 1630 ..... 15
p. 1636 ..... 15, 23
p. 1637 ..... 20
p. 1649 ..... 26
pp. 1650-1654 ..... 2
pp. 48165-48166 ..... 27
*1984 Annual Report of the Board of Trustees of the Federal Hospital Insurance Trust Fund*, H.R. Doc. 98-199, 98th Cong., 2d Sess. (1984).. 26
Office of Financial and Actuarial Analysis, Health Care Financing Administration, Department of Health and Human Services, *Annual Statistical Report No. 2082* (1984) ..... 26
S. Rep. 93-48, 93d Cong., 1st Sess. (1973) ..... 18
S. Rep. 93-318, 93d Cong., 1st Sess. (1973) ..... 18
S. Rep. 93-1297, 93d Cong., 2d Sess. (1974) ..... 17, 18, 19, 21, 22

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AMERICAN HOSPITAL ASSOCIATION, ET AL.

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## PETITION FOR A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

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The Solicitor General, on behalf of the Secretary of Health and Human Services, petitions for a writ of certiorari to review the judgment of the United States Court of Appeals for the Second Circuit in this case.

### OPINIONS BELOW

The order of the court of appeals summarily affirming the judgment of the district court (App., *infra*, 1a-3a) is not reported. The prior opinion of the court of appeals in *United States* v. *University Hospital of the State University of New York at Stony Brook* (App., *infra*, 4a-47a), upon which both the district court and court of appeals relied in this case, is reported at 729 F.2d 144. The memorandum and order of the district court (App., *infra*, 48a-49a) are reported at 585 F. Supp. 541.

### JURISDICTION

The judgment of the court of appeals was entered on December 27, 1984. The jurisdiction of this Court is invoked under 28 U.S.C. 1254(1).

## STATUTE AND REGULATIONS INVOLVED

1. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, provides:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of each such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of the Congress, and such regulation may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

2. 45 C.F.R. 84.55 and 45 C.F.R. Pt. 84, App. C, as added by 49 Fed. Reg. 1650-1654 (Jan. 12, 1984), are reproduced in the appendix to this petition (App. *infra*, 53a-72a).

## STATEMENT

1. a. On April 30, 1982, following public disclosure of an incident in Bloomington, Indiana, in which a newborn child with Down's Syndrome was permitted to starve to death after being denied life-saving surgery to repair a blocked esophagus, the President directed the Secretary of Health and Human Services to remind health care providers receiving federal financial assistance that Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap in programs or activities that receive federal financial assistance. See 49 Fed. Reg. 1622-1623 (1984); *American Academy of Pediatrics* v.

*Heckler*, 561 F. Supp. 395, 397 (D.D.C. 1983). On May 18, 1982, the Secretary sent such a notice to all covered health care providers. 47 Fed. Reg. 26027. The notice stated that "[t]here has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects" and that "[r]eports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome." *Ibid.*

Subsequently, on March 7, 1983, HHS promulgated interim final rules establishing certain procedures relating to the application of Section 504 to refusals to treat handicapped infants. 48 Fed. Reg. 9630. On April 14, 1983, these regulations were invalidated by the United States District Court for the District of Columbia in *American Academy of Pediatrics* v. *Heckler*, *supra*. Although the district court in that case was of the view that the broad language of Section 504 might well authorize some regulation of the provision of some types of medical care to handicapped newborns (561 F. Supp. at 402), it concluded that HHS's decision to waive the public comment period when it promulgated the regulations violated the Administrative Procedure Act and that the regulations were arbitrary and capricious because the administrative record failed to establish that several important factors had been adequately considered (*id.* at 403-404).

b. The Secretary then published new proposed regulations on July 5, 1983. 48 Fed. Reg. 30846. After receiving broad public comment,[1] the revised final regulations at issue here were published on January 12, 1984. 49 Fed. Reg. 1622.

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[1] HHS received almost 17,000 comments on the proposed regulations, more than 97% of which were favorable. 49 Fed. Reg. 1622-1623 (1984).

The regulations explain the basic applicability of Section 504 in this setting through interpretative guidelines, which establish four basic principles: (1) health care providers receiving federal financial assistance "may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment"; (2) treatment that is futile or will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant for purposes of Section 504; (3) reasonable medical judgments in selecting among alternative courses of treatment will be respected; and (4) where a parent withholds consent to treatment that is medically indicated, the hospital may not, solely on the basis of the infant's handicap, decline to report the matter to the appropriate child protective agency or to seek judicial review. 45 C.F.R. Pt. 84, App. C para. (a)(1)-(4).[2] The remainder of the regulations contains measures for the implementation of these principles.

The implementing regulations are tailored in a number of respects to foster a cooperative effort on the part of the federal government, state governments, the medical community, and private advocacy groups. For example, the

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[2] The interpretative guidelines also give illustrations of conduct that would and would not violate Section 504. For example, the guidelines reiterate the Department's position that withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome, when the withholding is based upon the anticipated future mental retardation of the child and when there are no medical contraindications, would constitute discrimination in violation of Section 504. But the guidelines also state that withholding of treatment for such conditions as anencephaly, spina bifida, and severe prematurity and low birth weight—when based on reasonable medical judgments that the treatment would be futile, too unlikely of success given complications in the particular case, create risks of potential harm to the infant, or merely prolong the act of dying—would not violate Section 504. 45 C.F.R. Pt. 84, App. C para. (a)(5)(i)-(iv).

regulations initiate new efforts to make the use of federal enforcement mechanisms unnecessary by encouraging hospitals to establish their own policies and procedures to implement the guiding principles. This approach follows the recommendation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 49 Fed. Reg. 1622, 1623-1625 (1984). In accordance with this recommendation, the Secretary developed a model for hospitals that wish to establish Infant Care Review Committees to assist in evaluating issues relating to the treatment of handicapped infants. 45 C.F.R. 84.55(a) and (f).

Under the proposed model, the Infant Care Review Committee [3] would develop and recommend to the hospital institutional policies concerning the withholding or withdrawal of treatment from infants with life-threatening conditions, including guidelines for management of certain categories of cases (*e.g.*, Down's Syndrome and Spina Bifida) and procedures to be followed in certain recurring circumstances (*e.g.*, brain death and parental refusal to consent to life-saving treatment). 45 C.F.R. 84.55(f)(3)(i). The Committee also would review specific cases where a preliminary decision has been made to withhold or withdraw life-sustaining treatment from patients in certain categories or where there is a disagreement between the treating physician and the family regarding such treatment, and the Committee would recommend that the hospital refer the case to an appropriate court or child protective agency if the Committee disagreed with the family's refusal to consent to treatment in a particular case. 45 C.F.R. 84.55(f)(3)(ii). In addition, the Committee would conduct a retrospective re-

[3] The Committee would be composed of a practicing physician, a practicing nurse, a hospital administrator, a representative of the legal profession, a representative of a disability group or a disability expert, a lay community member, and a member of the hospital's organized medical staff, who would serve as chairman. 45 C.F.R. 84.55(f)(2).

cord review of cases in which treatment had been withdrawn or withheld, in order to determine whether such instances were consistent with the hospital's policies. 45 C.F.R. 84.55(f)(1)(iii).

In accordance with the policy of involving state agencies in the process as well, the regulations require each state child protective services agency that receives federal financial assistance to establish methods of administration and procedures to assure that it utilizes its full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants. 45 C.F.R. 84.55(c). These methods and procedures must include a requirement that health care providers report circumstances that they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants; provisions for the state agency to review and, if necessary, investigate such reports; procedures for affording child protective services to medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the furnishing of necessary nourishment and medical treatment; and notification to HHS of each report of suspected medical neglect of an infant solely because of his handicap, including the nature of the state agency's investigation and final disposition of the matter. *Ibid.*

Finally, in order to facilitate investigation by HHS where necessary, the regulations provide for expedited access to records and facilities of the recipient hospital for investigative purposes when "necessary to protect the life or health of a handicapped individual." 45 C.F.R. 84.55(d). Similarly, when immediate action is necessary, the regulations allow for waiver of the usual 10-day waiting period prior to the initiation of judicial or other action to effect compliance. 45 C.F.R. 84.55(e). An appendix to the regulations sets forth guidelines for HHS investigations of reports of unlawful withholding of medical treatment, including provisions for consultation with the hospital's Infant Care Review Committee and meas-

ures to insure that any investigations are conducted promptly and with the least disruption possible. 45 C.F.R. Pt. 84, App. C. para. (b). The regulations also require recipient hospitals to post a notice, visible to nurses and other medical professionals, which (i) states that Section 504 prohibits the withholding of nourishment and medically beneficial treatment from handicapped infants based solely on their present or anticipated mental or physical impairments, and (ii) identifies the designated hospital official, the appropriate child protective services agency, and the HHS office that may be contacted to obtain further information or to report suspected noncompliance. 45 C.F.R. 84.55(b).

2. a. On April 6, 1983 the American Hospital Association, the Hospital Association of New York State, and Strong Memorial Hospital filed suit in the United States District Court for the Southern District of New York challenging the initial regulations that were promulgated by the Secretary on March 7, 1983. See page 3, *supra*. The district court entered a temporary restraining order barring enforcement of those regulations in New York State. *American Hospital Ass'n, et al.* v. *Heckler*, 83 Civ. 2638-CLB (Apr. 6, 1983). However, before a hearing could be held by the district court below, the United States District Court for the District of Columbia declared the regulations invalid on APA grounds in *American Academy of Pediatrics* v. *Heckler*, discussed at page 3, *supra*. On March 12, 1984, after the Secretary promulgated the new regulations at issue here, the plaintiffs filed an amended complaint challenging those regulations as beyond the Secretary's authority under Section 504. On the same date, a second suit was filed in the District Court for the Southern District of New York by the American Medical Association, the American Hospital Association, and others challenging the same regulations. The two suits were consolidated in the district court.

By memorandum and order dated May 23, 1984, the district court held that the regulations are beyond the

Secretary's statutory authority under Section 504 (App., *infra*, 48a-49a). In so holding, the court concluded that this case was directly controlled by the Second Circuit's decision in *United States* v. *University Hospital of the State University of New York at Stony Brook*, 729 F.2d 144 (1984) (App., *infra*, 4a-47a), discussed at pages 8-11, *infra*. On June 11, 1984, the district court entered its final judgment, which permanently enjoined the Secretary and her officers, agents, employees, and attorneys from any further implementation of the regulations and from taking any other action under Section 504 (including any pending investigation or other enforcement action) to investigate or regulate treatment decisions involving impaired newborn infants in any program receiving federal financial assistance (App., *infra*, 50a-52a).

b. In a brief per curiam order dated December 27, 1984, the court of appeals summarily affirmed the district court's judgment on the basis of the court of appeals' prior decision in *United States* v. *University Hospital* (App., *infra*, 1a-3a).[4]

3. a. In *United States* v. *University Hospital*, which both the district court and court of appeals regarded as controlling in this case, a divided panel of the Second Circuit held that Section 504 is wholly inapplicable to the withholding of medical treatment from handicapped infants. The court therefore held that the government was not entitled under existing regulations (45 C.F.R. 80.6(c), 84.61) to access to the hospital's records pertaining to a particular handicapped infant, Baby Jane Doe. HHS had received a complaint that Baby Jane Doe was being discriminatorily denied life-saving medical treatment on the basis of her handicap, and it sought

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[4] The Secretary recognized that this case was controlled in the court of appeals by the prior decision in *University Hospital*, and she therefore moved for initial en banc consideration of the instant case. The court of appeals denied that motion on August 22, 1984. The Secretary then moved for summary disposition of the appeal.

access to her medical records in order to investigate whether a violation of Section 504 had occurred.[5]

The court of appeals in *University Hospital* assumed, without deciding, that the hospital's receipt of Medicare and Medicaid funds constituted the receipt of "Federal financial assistance" that triggered the application of Section 504 to the withholding of medical treatment from Baby Jane Doe (App., *infra*, 16a-18a). Further, the court held that Baby Jane Doe was a "handicapped individual" for purposes of Section 504 (*id.* at 26a-28a). However, the majority held that Baby Jane Doe could not be considered to be an individual who was "otherwise qualified" for the hospital's services or was "subjected to discrimination" within the meaning of Section 504 (*id.* at 28a-39a).

According to the majority, "the phrase 'otherwise qualified' is geared toward relatively static programs or activities such as education, employment, and transportation systems. As a result, the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning" (App., *infra*, 30a (citations omitted)). Nor, in the majority's view, could the child be considered to be "subjected to discrimination," because "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a

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[5] Baby Jane Doe was born on October 11, 1983, with multiple birth defects, including myelomeningocele (exposed spinal cord membranes, commonly known as spina bifida), microcephaly (abnormally small head), and hydrocephalus (accumulation of fluid in the cranial vault). On advice of her initial pediatrician, Baby Jane Doe was admitted to University Hospital for corrective surgeries. After consulting with physicians at University Hospital, her parents withheld consent to surgeries to treat the spinal defect and to drain the water from the infant's skull, opting instead to administer antibiotics and dress the exposed spinal sac. University Hospital acquiesced in that decision. See *United States* v. *University Hospital of the State University of New York at Stony Brook*, 575 F. Supp. 607, 610 (E.D. N.Y. 1983).

particular decision was 'discriminatory'" (*ibid.*). The majority also declined to attach significant weight to the Secretary's interpretation of Section 504 in this setting, terming the regulatory history "inconclusive" (*id.* at 25a; see generally *id.* at 18a-25a). In addition, the majority read the legislative history to reflect a congressional concern primarily with access by the handicapped to federally assisted programs, and it relied on the absence of a specific statement in the legislative history that Section 504 applies to medical treatment decisions (*id.* at 31a-38a). Finally, the majority concluded that to require a hospital to petition a state court or to take other steps to override the parents' withholding of consent to treatment in a particular case would impose an "affirmative action" burden on the hospital, contrary to this Court's decision in *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979) (App., *infra*, 39a).

b. Judge Winter dissented (App., *infra*, 42a-47a). He concluded that because Congress explicitly patterned Section 504 after Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d *et seq.*, which prohibits discrimination on the basis of race in federally assisted programs, Congress had determined that, "so far as the administration of federal financial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race" (App., *infra*, 43a-44a). Judge Winter stressed that the government has never taken the position that it is entitled to override a medical judgment; "[i]ts position rather is that it is entitled under Section 504 to inquire whether a judgment in question is a *bona fide* medical judgment" (*id.* at 44a). Based on the statutorily mandated analogy to racial discrimination, Judge Winter concluded that the logic of the government's position is "about as flawless as a legal argument can be" (*ibid.*):

> A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment.

> So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. Finally, once the legislative analogy to race is acknowledged, the intrusion on state authority becomes insignificant.

Accordingly, Judge Winter would have reversed the judgment of the district court in *University Hospital* and remanded for a determination whether the hospital was a recipient of "Federal financial assistance" that triggered the application of Section 504 to the infant (*id.* at 47a).[6]

## REASONS FOR GRANTING THE PETITION

The court of appeals has held that the Secretary's regulations and interpretative guidelines concerning the application of Section 504 to the withholding or withdrawal of nutrition or medically beneficial treatment from an infant solely by reason of his handicap are invalid on their face. The court has held, in other words, that Section 504 does not apply to this entire category of cases, no matter how egregious the circumstances. Thus, to use one of the specific examples cited in the Secretary's interpretative guidelines,[7] Section 504 does not, in the court of appeals' view, prohibit a federally assisted hospital program from withholding life-saving surgery to correct an intestinal obstruction in an infant with Down's Syndrome, even if the hospital would not hesitate to perform the same surgery

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[6] Shortly after the court of appeals rendered its decision in *University Hospital*, the hospital disclosed that Baby Jane Doe had received corrective surgery for her life-threatening conditions (see page 5, *supra*) and had been discharged from the hospital. Accordingly, the United States elected not to petition for a writ of certiorari to review the judgment in that case.

[7] See 45 C.F.R. Pt. 84, App. C para. (a) (5) (i).

on a normal child and the hospital's failure to perform the surgery is based solely upon the mental retardation of the infant and thus solely upon his handicap.

The court of appeals' holding is flatly inconsistent with the language and purposes of Section 504 and with the Secretary's implementing regulations and interpretative guidelines, which are entitled to substantial deference. Nor does such an implied exception for all decisions concerning medical treatment of impaired newborn infants find any support in the legislative history of Section 504, which manifests an intent to adopt a broad bar to discrimination against the handicapped in federally assisted programs, specifically including those furnishing health services. Yet the court of appeals in this case has affirmed a sweeping nationwide injunction that purports to bar the Secretary from undertaking *any* investigation or enforcement actions under Section 504 with respect to *any* treatment decisions involving handicapped newborn infants in *any* program or activity receiving federal financial assistance. What is more, the court of appeals' view that Section 504 does not address decisions concerning the furnishing of medical treatment is not logically limited to infants whose impairments are severe, or even to infants. By thus suggesting that any decision by a physician or hospital relating to medical treatment is cloaked with blanket immunity from scrutiny under Section 504, the decision below calls into question the application of Section 504 to the furnishing of federally assisted health services to handicapped individuals generally. Review by this Court therefore is plainly warranted.

1. a. The starting point of analysis must of course be the language of Section 504 itself, for "we assume 'that the legislative purpose is expressed by the ordinary meaning of the words used.'" *Kosak* v. *United States*, No. 82-618 (Mar. 21, 1984), slip op. 5, quoting *American Tobacco Co.* v. *Patterson*, 456 U.S. 63, 68 (1982). See *Consolidated Rail Corp.* v. *Darrone*, No. 82-862 (Feb. 28, 1984), slip op. 7-9. Contrary to the court of appeals' view

(App., *infra*, 28a-31a), the language of Section 504 clearly prohibits a hospital program receiving such federal financial assistance as to bring it within the scope of the statute (see note 12, *infra*) from withholding nourishment or medically indicated treatment from a handicapped infant solely by reason of his handicap. Section 504 provides in relevant part:

> No otherwise qualified handicapped individual in the United States * * * shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance * * *.

The court of appeals in *University Hospital* held that an impaired newborn child is a "handicapped individual" for purposes of Section 504 (App., *infra*, 26a-28a). Although the court of appeals expressed reservations even about that conclusion—believing that the term might be understood to apply only to adults (*id.* at 26a-27a)—the statutory language in our view is so clear as to admit of no other interpretation.

The broad directive that "[n]o * * * handicapped individual" may be discriminated against itself suggests an all-inclusive coverage, without regard to the individual's age. Compare *North Haven Board of Education* v. *Bell*, 456 U.S. 512, 520 (1982). Moreover, the term "handicapped individual" is defined in broad terms to mean "*any person* who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 29 U.S.C. 706(7)(B) (emphasis added). Especially in light of the Secretary's 1977 regulations implementing Section 504 (see 42 Fed. Reg. 22677), there can be no question that the infants who are the subject of the concern giving rise to the regulations at issue here have "physical or mental impairment[s]" (App., *infra*, 26a)[8]

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[8] HHS regulations define the term "physical or mental impairment" to mean "(A) any physiological disorder or condition, cos-

and that those impairments substantially limit one or more of the infants' "major life activities." [9] Moreover, as the court of appeals observed (App., *infra*, 27a), "it would defy common sense" to rule that the Baby Jane Doe involved in *University Hospital* was not at least "regarded" by others as having such an impairment, and thus handicapped within the meaning of 29 U.S.C. 706(7)(B)(iii).

It also would seem clear that a handicapped newborn infant who, solely because of his handicap, is denied nourishment or treatment that would be medically beneficial is an "otherwise qualified" handicapped individual who has been "denied the benefits of" and "subjected to discrimination under" the federally assisted program within the meaning of Section 504. This Court stated in *Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979), that the "plain meaning" of the term otherwise qualified handicapped individual is "one who is able

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metic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and lymphatic; skin; and endocrine; or (B) any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities." 45 C.F.R. 84.3(j)(2)(i).

[9] HHS regulations define the term "major life activities" to mean "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 45 C.F.R. 84.3(j)(2)(ii). Although newborn infants obviously cannot perform some of these functions, others of those mentioned (*e.g.*, seeing, hearing, breathing and learning) are capable of being performed by infants. Moreover, this listing expressly is not exclusive (it refers to functions "such as" those listed), and it therefore readily embraces any functions or activities that are comparably "major" in the life of an infant. In *University Hospital*, for example, the court of appeals noted that Baby Jane Doe's rectal, bladder, leg, and sensory functions were all then presently impaired and that, with or without corrective surgery, she would experience severe mental retardation throughout her life (App., *infra*, 27a).

to meet all of a program's requirements in spite of his handicap." In *Davis* a deaf student was, because of her handicap, not qualified for admission to nursing school because she could not meet some of the educational program's basic physical requirements. Obviously, one need not possess any special qualifications to benefit from receiving nourishment. Similarly, in the context of the furnishing of health services, there ordinarily are no qualifications that a patient must meet other than to have the ability, in spite of his handicap, to benefit from medical treatment.[10] Accordingly, if an infant's handicapping condition would not prevent him from benefitting from, for example, corrective surgery, he must be considered "otherwise qualified." That is the principle HHS applied in adopting the regulations and interpretative guidelines at issue here.[11]

On this understanding, if a federally assisted hospital refused to furnish an infant who has a handicap (*e.g.*, Down's Syndrome) with treatment that would be medically beneficial (*e.g.*, surgery to remove an intestinal blockage (see note 2, *supra*)) and that would be performed for a child who is not handicapped, the infant quite clearly has, "solely by reason of his handicap," been "denied the benefits of" and been "subjected to discrimination under" the federally assisted program. Thus, contrary to the court of appeals' conclusion, the regulations and interpretative guidelines respondents challenge are firmly supported by the plain language of Section 504.[12]

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[10] See 45 C.F.R. 84.3(k)(4) (as regards health and other services, a qualified handicapped person is one "who meets the essential eligibility requirements for the receipt of such services"); 45 C.F.R. Pt. 84, App. A para. 5.

[11] "If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is 'otherwise qualified' to receive that treatment or service, and it may not be denied solely on the basis of the handicap." 49 Fed. Reg. 1636 (1984); see also *id.* at 1630.

[12] Section 504 prohibits discrimination only in a "program or activity receiving Federal financial assistance," but no question is

The majority in *University Hospital* attempted to avoid this conclusion by reasoning that the phrase "otherwise qualified" is geared toward relatively "static" pro-

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presented here regarding this aspect of the coverage of Section 504. Compare *Consolidated Rail Corp.* v. *Darrone*, slip op. 11-12; *North Haven Board of Education* v. *Bell*, 456 U.S. at 540. The district court in *University Hospital* held that the hospital program's receipt of payments for the furnishing of medical treatment under the Medicaid and Medicare Programs, 42 U.S.C. 1395 *et seq.*, 1396 *et seq.*, constituted the receipt of "Federal financial assistance" that triggered the application of Section 504, whether or not Baby Jane Doe herself was a beneficiary under the Medicaid Program. 575 F. Supp. at 612-613. Compare *Grove City College* v. *Bell*, No. 82-792 (Feb. 28, 1984), slip op. 15 n.21. This holding is consistent with HHS's longstanding position (see 45 C.F.R. Pt. 84, App. A paras. 1, 2) and with the holding of the only court of appeals to have extensively considered the question. See *United States* v. *Baylor University Medical Center*, 736 F.2d 1039, 1042-1049 (5th Cir. 1984), cert. denied, No. 84-525 (Jan. 21, 1985).

However, the court of appeals in *University Hospital* declined to resolve this question. It assumed for purposes of the decision that the hospital's actions pertaining to Baby Jane Doe *were* under a program or activity receiving federal financial assistance by virtue of the hospital's receipt of Medicare and Medicaid funds (App., *infra*, 16a-18a), but it held that Section 504 did not in any event address the question of discrimination in the medical treatment of handicapped infants (*id.* at 18a-41a). The district court and court of appeals in the instant case entered judgment in favor of respondents on the basis of that holding in *University Hospital* (*id.* at 2a, 49a), and they therefore likewise had no occasion to consider whether a hospital's receipt of Medicare and Medicaid payments made Section 504 applicable to the furnishing of medical services to patients in covered programs.

Moreover, the regulations that respondents challenge in this suit (45 C.F.R. 84.55 and Pt. 84, App. C) are quite general and do not even address the question of what constitutes a program or activity receiving federal financial assistance for purposes of Section 504. That question therefore can be addressed only in the context of the application of Section 504 and the regulations and guidelines at issue here to a particular hospital. In such a case, it would be appropriate to consider not only the particular hospital's receipt of Medicare and Medicaid funds, but also other forms of federal financial assistance, such as Hill-Burton and other construction funds. See, *e.g.*, 42 U.S.C. 291 *et seq.*

grams or activities such as education, employment, and transportation systems, and cannot be applied in the comparatively "fluid" context of medical treatment decisions without "distorting its plain meaning" (App., *infra*, 30a). But it is the majority below that is distorting the plain meaning of Section 504, because the supposed distinction between "static" and "fluid" contexts finds no support whatever in the statutory language. Section 504 broadly prohibits discrimination in "*any* program or activity receiving Federal financial assistance" ((emphasis added); see *Consolidated Rail Corp.* v. *Darrone*, slip op. 7), a phrase that clearly encompasses the furnishing of health services. See S. Rep. 93-1297, 93d Cong., 2d Sess. 38 (1974); 45 C.F.R. 84.3(h), 84.52.

By its use of the term "fluid," the majority apparently meant that a handicapped infant's need for a particular course of treatment may vary with changes in the child's physical condition. Where such fluidity is present, it may appropriately inform the range of reasonable medical alternatives and thereby support additional deference to a physician's professional medical judgment. But the fact that some physical conditions may fluctuate does not support a wholesale exemption from Section 504 for *all* decisions relating to medical treatment. There was, for example, nothing "fluid" about the Bloomington Baby Doe's need for corrective esophageal surgery to enable him to receive nourishment.[13] By the same token, programs and activities other than the furnishing of health services are not necessarily "static," as the majority in *University Hospital* seemed to believe. For example, in a federally assisted educational program, decisions that

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[13] Moreover, the potentially "fluid" nature of a patient's condition would not immunize a medical treatment decision from scrutiny to determine whether it was based on the race of the patient, in violation of Title VI. Because Section 504 was patterned after Title VI (see pages 19-20, *infra*), there is no reason to believe that Congress intended to confer such a blanket immunity under Section 504 either.

affect a handicapped child are made every day, and adjustments might have to be made in that program to take into account fluctuations in the child's physical or mental condition. In short, the distinction the majority posited finds no basis in the statutory language, the policies of Section 504, or common sense.

b. The legislative history of Section 504 also fully supports the validity of the regulations. The legislative history of Section 504 as originally enacted is relatively sparse, but it describes the Section in broad terms that contain no suggestion that Congress intended to create the exception fashioned by the court of appeals.[14] The breadth of Section 504 is further stressed in S. Rep. 93-1297, 93d Cong., 2d Sess. (1974), which was issued in connection with the 1974 addition of the definition of the term "handicapped individual" in 29 U.S.C. 706 (7)(B) and upon which this Court repeatedly has relied as an authoritative exposition of the congressional intent underlying Section 504.[15] That report states that Section 504 "was enacted to prevent discrimination against all handicapped individuals * * * in relation to Federal assistance in employment, housing, transportation, education, *health services*, or any other Federally-assisted programs" and "constitutes the establishment of a *broad government policy* that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap." S. Rep. 93-1297, *supra*, at 38-39 (emphasis added).

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[14] See, *e.g.*, S. Rep. 93-48, 93d Cong., 1st Sess. 55, 80 (1973); S. Rep. 93-318, 93d Cong., 1st Sess. 50, 70 (1973); 118 Cong. Rec. 30681 (1972) (remarks of Sen. Randolph); *id.* at 32310 (remarks of Sen. Humphrey); 119 Cong. Rec. 5862 (1973) (remarks of Sen. Cranston).

[15] See *Southeastern Community College* v. *Davis*, 442 U.S. at 406 n.6; *Community Television* v. *Gottfried*, 459 U.S. 498, 509 (1983); *Consolidated Rail Corp.* v. *Darrone*, slip op. 10 n.15; *Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985), slip op. 5 n.7, 16 n.24; see also *id.* at 18-19 & n.27.

In addition, the Senate Report underscores what is in any event evident from the language of Section 504: that it is patterned directly after Title VI of the Civil Rights Act of 1964 (see S. Rep. 93-1297, *supra*, at 39) and that Congress therefore concluded that discrimination because of handicap should be viewed as "similar to discrimination because of race" (*id.* at 38). See *Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985), slip op. 5 & n.7, 7-8 n.13; *Consolidated Rail Corp* v. *Darrone*, slip op. 5-6, 10 n.16; *Community Television* v *Gottfried*, 459 U.S. at 509. This congressionally mandated analogy to racial discrimination, at least in the context of intentional discrimination (compare *Alexander* v. *Choate*, slip op. 6-11), further reinforces the validity of the regulations at issue here. The Secretary's interpretative guidelines expressly provide that reasonable medical judgments will be respected. 45 C.F.R. Pt. 84, App. C para. (a)(3). But as Judge Winter expalined in his dissent in *University Hospital* (App., *infra*, 44a), not every decision by a hospital that happens to relate to the furnishing of medical treatment is perforce a bona fide medical judgment that is automatically immune from scrutiny under the antidiscrimination laws. Surely, for example, a federally assisted hospital would not be free under Title VI to decline to perform surgery to remove an intestinal obstruction in an infant solely because of his race. Although such a decision would relate to medical treatment, it would not be a bona fide medical judgment. It is equally unlawful under Section 504 for the hospital to decline to perform the same surgery on an infant solely because of his handicap (*e.g.*, Down's Syndrome). Moreover, just as a hospital could not, under Title VI, decline solely because of the child's race to take appropriate steps to override a parental withholding of consent to needed treatment, a hospital cannot, under Section 504, decline to do so solely because of the child's handicap.

The panel majority in *University Hospital* believed that the analogy to racial discrimination "breaks down," reasoning that "[w]here the handicapping condition is

related to the condition[s] to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'" (App., *infra*, 30a-31a). Even assuming this observation were correct as an analytical matter (but see note 17, *infra*), it says nothing about those instances in which the handicapping condition is *not* necessarily related to the impairment to be treated. In the widely publicized Bloomington Baby Doe case, a decision was made to forego routine surgery on an intestinal blockage of a newborn child with Down's Syndrome because such treatment would not cure the child's mental retardation.[16] The child starved to death. The intestinal blockage plainly was separable from any retardation associated with Down's Syndrome that would have remained after the corrective surgery, and if the infant had not been handicapped, the hospital surely would have taken steps to provide the routine corrective surgery. There is no difficulty in determining that such a decision is "discriminatory." [17]

The court of appeals in *University Hospital* also drew a negative inference from the fact that medical treatment decisions were not specifically mentioned in the legislative history of Section 504 (App., *infra*, 31a-35a).

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[16] *In re Infant Doe*, No. GU 8204-004A (Apr. 12, 1982), writ of mandamus dismissed *sub nom. State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (Ind. Cir. Ct. May 27, 1982) (case mooted by child's death). There are other documented instances of children with Down's Syndrome being denied routine corrective surgery for intestinal blockages. See 48 Fed. Reg. 30847 (1983).

[17] As the Secretary explained when she promulgated the regulations at issue here, the same analytical framework applies where the handicapping condition and the condition to be treated are the same. In such a case, the "handicap" is the physical or mental impairment that would remain *after* completion of the treatment involved. The Secretary acknowledged that application of the analytical framework may be more difficult in such circumstances because of the interrelatedness of the medical considerations. 49 Fed. Reg. 1637 (1984). But the existence of some difficult cases scarcely justifies the wholesale exclusion fashioned by the court of appeals for *all* medical treatment decisions.

But Congress's failure to advert expressly to a particular application that the words and purpose of the statute clearly embrace does not negate that application. See, *e.g.*, *Jefferson County Pharmaceutical Ass'n* v. *Abbott Laboratories*, 460 U.S. 150, 159 n.18 (1983), and cases cited. See also *United States* v. *Weber Aircraft Corp.*, No. 82-1616 (Mar. 20, 1984), slip op. 8, 9-11. That is especially so where, as here, Congress has deliberately enacted a sweeping policy covering a broad range of programs and left to the agencies concerned the responsibility to elaborate upon that policy in particular contexts. See pages 21-22, *infra*.

Equally without merit is the court of appeals' reliance on what it believed was Congress's exclusive concern in the legislative history with access by handicapped persons to federally assisted programs (App., *infra*, 33a-35a). Section 504 on its face addresses not only the matter of access (by providing that a handicapped person may not "be excluded from the participation in" the program or activity); it further provides that a person may not be "denied the benefits of" or be "subjected to discrimination under" the program, even if he does have some measure of access to it. In other words, Section 504 requires "evenhanded treatment" of handicapped individuals. *Alexander* v. *Choate*, slip op. 16. Section 504 should be " 'accord[ed] * * * a sweep as broad as its language,' " and courts should not "read into [the statute] a limitation [*i.e.*, an exclusion for medical treatment decisions] not apparent on its face." *Grove City College* v. *Bell*, No. 82-792 (Feb. 28, 1984), slip op. 8, quoting *North Haven Board of Education* v. *Bell*, 456 U.S. at 521.

c. The court of appeals also failed to accord any deference to the Secretary's regulations and guidelines implementing Section 504 (App., *infra*, 25a). Its decision in this respect is contrary to the congressional intent that the Secretary promulgate such regulations (S. Rep. 93-1297, *supra*, at 39-40) and to this Court's recognition

that "these regulations [are] an important source of guidance on the meaning of § 504." *Alexander* v. *Choate*, slip op. 16 n.24; see also *Southeastern Community College* v. *Davis*, 442 U.S. at 413. The regulations promulgated by the Secretary in 1977 expressly provide that Section 504 applies to federally assisted programs for the furnishing of health services (45 C.F.R. 84.4, 84.52, 84.53), and the Secretary made clear at the time of promulgation that medical treatment decisions are covered.[18] The original regulations did not specifically mention the subcategory of treatment decisions involving handicapped newborn infants, but this obviously does not mean that it or any other subcategory was implicitly excluded from coverage.

The regulations promulgated in 1984, at issue here, were intended simply to provide further guidance regarding the application of the general principles of nondiscrimination in this particular setting. Congress intended that the Secretary would have "substantial leeway to explore areas in which discrimination against the handicapped posed particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander* v. *Choate*, slip op. 16 n.24, citing S. Rep. 93-1297, *supra*, at 40-41, 56. See also *id.* at 19-20 n.32. This is a continuing responsibility of the Secretary that may require her to respond to reports of apparent discrimination, such as the Bloomington Baby Doe case that led to the regulations at issue here. See *Southeastern Community College* v. *Davis*, 442 U.S. at 413 (emphasis added) ("Identification of those instances where a refusal to accommodate the needs of a disabled person amounts to discrimination against the handicapped

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[18] See 45 C.F.R. Pt. 84, App. A para. 36:

> [A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

*continues* to be an important responsibility of HEW."); *Community Television* v. *Gottfried*, 459 U.S. at 512; cf. *Lau* v. *Nichols*, 414 U.S. 563 (1974); *Guardians Ass'n* v. *Civil Service Comm'n of New York City*, 463 U.S. 582 (1983).

The court of appeals believed that the Secretary had disclaimed any authority with respect to medical treatment decisions when the present Section 504 regulations were proposed in 1976, and it discounted the Secretary's current view on that ground (App., *infra*, 18a-19a, 25a). The court of appeals was wrong. All that the Secretary determined in 1976 was that Section 504 did not authorize regulations "concerning adequate and appropriate psychiatric care or safe and humane living conditions for persons institutionalized because of handicap or concerning payment of fair compensation to patients who perform work." 41 Fed. Reg. 29548, 29559 (1976). In other words, Section 504 was not understood to confer on institutionalized persons a right to safe conditions or to treatment.[19] This conclusion of course was consistent with the fact that Section 504 is concerned only with discrimination in the *relative* treatment of handicapped and nonhandicapped persons and does not confer any *absolute* right to receive particular services or benefits under federally assisted programs. The Secretary did not suggest that Section 504 is inapplicable even where there *is* discrimination between the handicapped and nonhandicapped with respect to the furnishing of particular medical services.

When the Secretary promulgated the instant regulations in 1984, she distinguished the comments during the rulemaking proceedings in 1976 on the ground just discussed (49 Fed. Reg. 1636 (1984)), and that interpretation of the Department's prior action is itself entitled to substantial deference. *Udall* v. *Tallman*, 380 U.S. 1, 16-

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[19] That distinct question was addressed by this Court as a constitutional matter in *Youngberg* v. *Romeo*, 457 U.S. 307 (1982).

17 (1965). Moreover, the fact that the Secretary was of the view after 1977 that Section 504 *does* apply to the discriminatory withholding of medical treatment from a handicapped infant is demonstrated by the fact that in May 1980, HHS formally resolved a Section 504 complaint against a hospital arising out of the death in 1979 of an infant with Down's Syndrome who had an intestinal blockage. In the compliance agreement, the hospital committed itself to report to the state child protective services agency any cases involving a lack of parental consent to medically indicated treatment for handicapped infants in the same manner as it reports similar cases involving nonhandicapped children. See 48 Fed. Reg. 30847-30848 (1983). Thus, the 1984 regulations the court of appeals invalidated do not reflect a new administrative interpretation of Section 504, much less a reversal of a prior interpretation, as the court of appeals believed. Compare *General Electric Co.* v. *Gilbert*, 429 U.S. 125, 142-143 (1976).

d. The final argument on which the panel majority in *University Hospital* relied was that to require a hospital to seek a court order or take other appropriate steps where the parents have refused to consent to life-saving treatment would constitute an "onerous affirmative action burden" that is impermissible under *Southeastern Community College* v. *Davis* (App., *infra*, 39a). This conclusion was based on a misunderstanding of the Secretary's position, a misinterpretation of *Davis*, and a gross exaggeration of the burden involved. *Davis* held that Section 504 does not obligate a university to make "substantial modifications" in its nursing program to accommodate the needs of a deaf student (442 U.S. at 413). See *Alexander* v. *Choate*, slip op. 13 n.20. It has been the Secretary's consistent position—reflected in the resolution of the 1980 complaint, just discussed (see page 23, *supra*)—that Section 504 requires a hospital to initiate steps to override a parental withholding of con-

sent to life-saving treatment for a handicapped child only if the hospital would have done so for a nonhandicapped child. Thus, Section 504 imposes no new "affirmative action" obligation on a hospital; it imposes only the "burden" of nondiscrimination.

Nor can the taking of the necessary steps in such circumstances be viewed as an impermissibly "onerous" burden on the hospital, especially when weighed against the consequences for the child. Virtually all hospitals are prepared to and do take steps to assure treatment when, for example, religious convictions prohibit the parents of a newborn infant from consenting to medical treatment necessary to the child's survival. Nor is there any doubt that most hospitals would not hesitate to take such steps in the case of a parental refusal to consent to a routine procedure, such as a blood transfusion, necessary to save the life of an otherwise normal and healthy child. It ordinarily would not even be necessary for the hospital to assume responsibility for litigation on the question. The hospital often might fulfill its obligation to afford even-handed treatment for a handicapped child simply by notifying the state child protective services agency, which in turn could investigate the matter and seek any necessary court order.

2. As we have explained, the decision of the court of appeals creating an implied exception from the coverage of Section 504 for all medical treatment decisions involving handicapped newborn infants is flatly inconsistent with the text, purposes, and legislative history of the statute and with the Secretary's implementing regulations and guidelines. The court's error is compounded because this case involves a sweeping nationwide injunction that purports to prohibit the Secretary from undertaking *any* investigation or enforcement action with respect to *any* treatment decision involving an impaired newborn infant in *any* federally assisted program (App., *infra*, 52a). The court below therefore has effectively barred any federal role whatever under Section 504—even of an oversight nature—with regard to the withholding of medi-

cally beneficial treatment from handicapped infants,[20] despite the receipt by hospitals in this country of billions of dollars annually in federal financial assistance under the Medicare and Medicaid Program alone.[21]

As HHS's study of this matter demonstrates (see 48 Fed. Reg. 30847-30848 (1983)), refusals to treat even moderately handicapped newborns has been more than just a rare occurrence. The protection that the Secretary's regulations afford these infants is significant, and the absence of such protection may, in some cases, be life-threatening. See 49 Fed. Reg. 1649 (1984). For this reason, and in light of the nationwide impact of the decision below and the resulting absence of a potential for a circuit conflict that might make the issue ripe for review at a later date, the court of appeals' erroneous invalidation of the entire regulatory program should not be permitted to stand.[22]

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[20] The *University Hospital* case underscores this point. HHS had not determined in that case that a violation of Section 504 had occurred as a result of the withholding of surgery from Baby Jane Doe. HHS required access to the relevant documents to evaluate the actions of hospital personnel. The court of appeals held, however, that HHS, which administered the substantial payments the hospital received, could not even obtain the information necessary to assess the situation.

[21] In fiscal year 1983, in excess of $38 billion was expended under Part A of the Medicare Program, which principally covers hospital services (*1984 Annual Report of the Board of Trustees of the Federal Hospital Insurance Trust Fund*, H.R. Doc. 98-199, 98th Cong., 2d Sess. 15 (1984)), and in excess of $32 billion was expended under the Medicaid Program, which covers both inpatient and outpatient services (Office of Financial and Actuarial Analysis, Health Care Financing Administration, Department of Health and Human Services, *Annual Statistical Report No. 2082* (1984)).

[22] On October 9, 1984, Congress passed amendments to the Child Abuse Prevention and Treatment Act (42 U.S.C. 5101 *et seq.*). See Pub. L. No. 98-457, 98 Stat. 1749 *et seq.* In those amendments Congress required that a state child protective services agency, in order to be eligible for federal grants under that Act, must establish procedures for receiving and responding to reports "of medical neglect

Moreover, the court of appeals' view that Section 504 does not apply in what it termed the "fluid" context of medical treatment decisions is not logically limited to infants with life-threatening or other severe conditions, or even to infants. It therefore calls into question the applicability of Section 504 to medical treatment decisions affecting handicapped individuals generally. In addition, the court of appeals' suggestion that Section 504 is limited only to matters of access by the handicapped, or is confined by reference to the particular examples of dis-

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(including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions) * * *" (§ 122, 98 Stat. 1752). (Similar state procedures are required under the Secretary's Section 504 regulations at issue here. See 45 C.F.R. 84.55(c).).

These new amendments do not, either practically or legally, obviate the need for review in this case. The amendments only require the state child protective agency to have in place procedures for receiving and investigating possible cases of failure to treat handicapped infants. The role of HHS under the amendments is only to insure that the state procedures are in place and are followed by the state agency. The amendments, unlike Section 504, place no independent federal duty on hospitals and other providers of services with regard to the treatment of handicapped infants. The application of Section 504 in this setting therefore is critical to ensure that hospitals also have an obligation under federal law to assure that handicapped infants are treated in an evenhanded manner and to assure, where necessary, the opportunity for direct investigation and enforcement by HHS regarding particular cases of discriminatory withholding of medically indicated treatment from handicapped infants.

Moreover, Section 127(a) of the Child Abuse Amendments of 1984 (98 Stat. 1754) states that "[n]o provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973." See also 130 Cong. Rec. S11699 (daily ed. Sep. 21, 1984) (letter of Sen. Hatch, et al.). The new legislation therefore does not affect the legal or practical importance of this case, which will effectively establish the applicability of Section 504 to hospital treatment decisions. See also 49 Fed. Reg. 48165-48166 (Dec. 10, 1984) (discussing interaction between Child Abuse and Treatment Act Amendments and Section 504).

criminatory treatment that were expressly mentioned in the legislative history, could adversely affect the enforcement of Section 504 outside of the context of medical treatment. Finally, the court's analysis of these issues could impede enforcement of other antidiscrimination statutes that are worded identically to Section 504, such as Title VI of the Civil Rights Act of 1964, regarding discrimination on the basis of race in the furnishing of medical services and other matters. Review by this Court therefore is plainly warranted.

## CONCLUSION

The petition for a writ of certiorari should be granted.

Respectfully submitted.

CHARLES FRIED
*Acting Solicitor General* *

WM. BRADFORD REYNOLDS
*Assistant Attorney General*

CHARLES J. COOPER
*Deputy Assistant Attorney General*

EDWIN S. KNEEDLER
*Assistant to the Solicitor General*

WALTER W. BARNETT
MARK L. GROSS
*Attorneys*

MARCH 1985

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* The Solicitor General is disqualified in this case.

## APPENDIX A

# UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

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At a stated Term of the United States Court of Appeals for the Second Circuit, held at the United States Courthouse in the City of New York, on the 27th day of December one thousand nine hundred and eighty-four.

Present: HONORABLE JON O. NEWMAN,
HONORABLE GEORGE C. PRATT,
HONORABLE JOHN W. PECK,*
Circuit Judges.

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84-6211

AMERICAN HOSPITAL ASSOCIATION, ET AL.,
PLAINTIFF-APPELLEES

*v.*

MARGARET M. HECKLER, Secretary,
United States Department of Health and
Human Services, DEFENDANT-APPELLANT

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* Of the United States Court of Appeals for the Sixth Circuit, sitting by designation.

84-6213

AMERICAN MEDICAL ASSOCIATION, ET AL.,
PLAINTIFFS-APPELLEES

*v.*

MARGARET M. HECKLER, Secretary,
Department of Health and Human Services,
DEFENDANT-APPELLANT

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[Filed Dec. 27, 1984]

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ORDER

The appellant, the Secretary of Health and Human Services, has moved for summary disposition, without briefing or oral argument, of her appeal from a judgment of the District Court for the Southern District of New York (Charles L. Brieant, Judge). The judgment declared invalid and enjoined enforcement of regulations, purportedly promulgated pursuant to section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982), concerning medical treatment of handicapped infants. The Secretary acknowledges that Judge Brieant's decision and this panel's affirmance of it are compelled by this Court's prior decision in *United States v. University Hospital*, 729 F.2d 144 (2d Cir. 1984).

Having reviewed the briefs, we agree that summary disposition without oral argument is appropri-

ate. Accordingly, the judgment of the District Court is affirmed.

/s/ John O. Newman

/s/ George C. Pratt

/s/ John W. Peck (per J.O.N.)
Circuit Judges

*N.B. Since this statement does not constitute a formal opinion of this court and is not uniformly available to all parties, it shall not be reported, cited or otherwise used in unrelated cases before this or any other court.*

**APPENDIX B**

UNITED STATES COURT OF APPEALS
FOR THE SECOND CIRCUIT

August Term 1983

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Docket No. 83-6343

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UNITED STATES OF AMERICA, PLAINTIFF-APPELLANT

*—against—*

UNIVERSITY HOSPITAL, STATE UNIVERSITY OF NEW YORK AT STONY BROOK, DEFENDANT-APPELLEE

PARENTS OF BABY JANE DOE,
INTERVENORS-DEFENDANTS-APPELLEES

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No. 679

Argued: December 2, 1983

Decided: 2-23-84

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Before: WINTER and PRATT, Circuit Judges, and METZNER, District Judge *.

Appeal from a summary judgment entered in the United States District Court for the Eastern District of New York (Leonard D. Wexler, *Judge*), denying the United States Department of Health and Human Services access to certain medical records maintained by defendant University Hospital.

Affirmed. Judge Winter dissents in a separate opinion.

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* Hon. Charles M. Metzner, of the United States District Court for the Southern District of New York, sitting by designation.

PRATT, *Circuit Judge*:

This expedited appeal presents the question whether Section 504 of the Rehabilitation Act of 1973, as amended, 29 U.S.C. § 794 (Supp. V 1981), and one of its implementing regulations, 45 C.F.R. § 84.61 (1982) (incorporating 45 C.F.R. § 80.6(c) (1982)), authorize the United States Department of Health and Human Services (HHS) to obtain access to medical records maintained by defendant University Hospital concerning a seriously deformed newborn infant, identified only as Baby Jane Doe, whose parents have refused to consent to certain surgical procedures necessary to prolong the infant's life. The United States District Court for the Eastern District of New York (Leonard D. Wexler, *Judge*) ruled that HHS was not entitled to the records and entered summary judgment in favor of University Hospital. For the reasons set forth below, we affirm.

I.

Baby Jane Doe was born on October 11, 1983 at St. Charles Hospital in Port Jefferson, New York. She was suffering from multiple birth defects, the most serious of which were myelomeningocele, commonly known as spina bifida, a condition in which the spinal cord and membranes that envelop it are exposed; microcephaly, an abnormally small head; and hydrocephalus, a condition characterized by an accumulation of fluid in the cranial vault. In addition, she exhibited a "weak face", which prevents the infant from closing her eyes or making a full suck with her tongue; a malformed brain stem; upper extremity spasticity; and a thumb entirely within her fist.

As a result of the spina bifida, the baby's rectal, bladder, leg, and sensory functions were impaired.

Due to the combination of microcephaly and hydrocephalus, there was an extremely high risk that the child would be so severely retarded that she could never interact with her environment or with other people.

At the direction of the first pediatric neurosurgeon to examine her, the baby was immediately transferred to University Hospital for dual surgery to correct her spina bifida and hydrocephalus. Essentially, this would entail excising a sac of fluid and nerve endings on the spine and closing the opening, and implanting a shunt to relieve pressure caused by fluid build-up in the cranial cavity. The record indicates that these dual, corrective surgical procedures were likely to prolong the infant's life, but would not improve many of her handicapping conditions, including her anticipated mental retardation.

After consulting with several physicians, nurses, religious advisors, a social worker, and members of their family, the parents of the baby decided to forego the corrective surgery. Instead, they opted for a "conservative" medical treatment consisting of good nutrition, the administration of antibiotics, and the dressing of the baby's exposed spinal sac.

Litigation surrounding Baby Jane Doe began on October 16, when A. Lawrence Washburn, Jr., a Vermont attorney unrelated to the child and her family, commenced a proceeding in New York State Supreme Court seeking appointment of a guardian *ad litem* for the child and an order directing University Hospital to perform the corrective surgery. The court appointed William E. Weber as guardian *ad litem* and held an evidentiary hearing on October 19 and 20 to determine whether Baby Jane Doe was "in need of immediate surgical procedures to preserve

her life". Following the hearing, at which University Hospital and the parents of the child were represented, the court concluded that surgery was necessary and ordered that it be performed.

One day later the Appellate Division of the New York Supreme Court reversed the decision of the trial court and dismissed the proceeding. The Appellate Division found that the "concededly concerned and loving parents have made an informed, intelligent, and reasonable determination based upon and supported by responsible medical authority." As the court elaborated:

> The record confirms that the failure to perform the surgery will not place the infant in imminent danger of death, although surgery might significantly reduce the risk of infection. On the other hand, successful results could also be achieved with antibiotic therapy. Further, while the mortality rate is higher where conservative medical treatment is used, in this particular case the surgical procedures also involve a great risk of depriving the infant of what little function remains in her legs, and would also result in recurring urinary tract and possibly kidney infections, skin infections and edemas of the limbs.

Thus, the Appellate Division determined that the parents' decision was in the best interest of the infant and that there was, therefore, no basis for judicial intervention.

On October 28, the New York Court of Appeals affirmed the decision of the Appellate Division, relying on different grounds. Since the petitioner had no direct interest in or relationship to any party and had failed to contact the State Department of Social

Services, which has primary responsibility under New York law for initiating child neglect proceedings, and since the trial court also had failed to seek that department's investigative assistance, the Court of Appeals found "no precedent or authority" for the proceeding. Accordingly, the Court of Appeals ruled that the trial court had abused its discretion by permitting the proceeding to go forward.

While the state court proceedings were still in progress, the federal government entered the picture. On October 19, HHS received a complaint from an unidentified "private citizen" that Baby Jane Doe was being discriminatorily denied medically indicated treatment on the basis of her handicaps. HHS referred the complaint to the New York State Child Protection Services, the state agency specifically responsible for investigating suspected incidents of child abuse, mistreatment, and neglect. On November 7, that agency concluded that there was no cause for state intervention.

Meanwhile, HHS obtained a copy of the record of the state court proceedings, which contained the child's medical records through October 19. The record was forwarded to and personally reviewed by the Surgeon General of the United States, who determined, among other things, that:

> An appropriate determination concerning whether the current care of Infant Jane Doe is within the bounds of legitimate medical judgment, rather than based solely on a handicapping condition which is not a medical contraindication to surgical treatment, cannot be made without immediate access to, and careful review of, current medical records and other sources of infor-

mation within the possession or control of the hospital.

Beginning on October 22, HHS repeatedly requested University Hospital to make available for inspection all of Baby Jane Doe's medical records since October 19. HHS based its authority to conduct an investigation on section 504 of the Rehabilitation Act, which provides in pertinent part that "[n]o otherwise qualified handicapped individual * * * shall, solely by reason of his handicap, * * * be subjected to discrimination under any program or activity receiving Federal financial assistance * * *". HHS further relied on 45 C.F.R. § 80.6(c), as incorporated by 45 C.F.R. § 84.61, which states:

> (c) *Access to sources of information.* Each recipient [of Federal financial assistance] shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this part. * * * Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part. * * *

University Hospital refused to honor HHS's requests, basing its decision in part on the refusal of the parents to release the records and in part on "serious concerns both as to the Department's jurisdiction and the procedures the Department has employed in initiating an inquiry."

The government then brought this action on November 2, alleging that University Hospital had violated section 504 and 45 C.F.R. § 80.6(c) by refusing

to allow HHS access to information concerning the medical care and hospital services being rendered to Baby Jane Doe. After the parents had intervened as defendants, and after the district court had granted the government's request to expedite the proceedings, both the hospital and the parents moved to dismiss the complaint, arguing, among other things, that (1) congress did not intend section 504 to reach decisions regarding health care services provided to infants; (2) section 504 imposes no affirmative treatment obligations on the hospital beyond providing handicapped persons equal access to its facilities, which the hospital had done; (3) medicare and medicaid reimbursements do not constitute "Federal financial assistance" within the meaning of section 504; (4) Baby Jane Doe's medical records were protected from disclosure by both her and her parents' federal constitutional privacy rights; and (5) the failure of the federal government to intervene in the state court proceedings barred the instant action under the doctrine of laches. Among the papers submitted in support of these motions was the entire record of the state court proceedings.

The government cross-moved for summary judgment, contending that HHS was entitled to the requested records because (1) the hospital's neonatal unit was a "recipient" of "Federal financial assistance" in the form of medicaid and (2) under 45 C.F.R. § 80.6(c) any such "recipient" was required to allow HHS access to information necessary to the discharge of the agency's statutory obligation to insure compliance with section 504.

Following oral argument on November 17, during which the government conceded that it had found no evidence of discrimination in the records covering

the period through October 19, the district court ruled that defendants were entitled to summary judgment. The court first rejected defendants' claims that (1) the suit was barred by laches; (2) access to the records was barred by New York's physician-patient evidentiary privilege; and (3) medicare and medicaid do not constitute "Federal financial assistance" within the meaning of section 504. Further, the court ruled that the entire hospital, not just its neonatal unit, was the "program or activity" covered by the statute.

Noting that 45 C.F.R. § 80.6(c) requires recipients of federal funds to provide HHS "access to such records 'as may be pertinent to ascertain compliance with' " section 504, the district court next reasoned that "if a recipient of federal financial assistance is clearly not violating [section 504] by discriminating against handicapped persons, the Department of Health and Human Services may not obtain access to the records of such recipient * * *". The court then turned to what it considered the central question: "whether, from the papers submitted to the Court, it can be clearly determined that the defendant University Hospital has not violated the statute by discriminating against a handicapped person." Emphasizing that the hospital "has at all times been willing to perform the surgical procedures in question", but "lacks the legal right to perform such procedures" in the absence of parental consent, the court concluded that the hospital "failed to perform the surgical procedures in question, not because Baby Jane Doe is handicapped, but because her parents have refused to consent to such procedures." Thus, in the court's view, "the failure of the defendant University Hospital to perform the surgical pro-

cedures cannot possibly be regarded as a violation of the Rehabilitation Act."

In any case, the court went on, "the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child." According to the court, this precluded any possibility of liability on the part of the hospital.

On appeal, the government, supported by various *amici*, argues that the district court erroneously required HHS "to make an advance evidentiary showing on the ultimate issue of unlawful conduct as a condition to securing the very materials necessary to reach a determination on that issue". In any event, the government contends, the district court's finding that no discrimination occurred could only have applied to the period up to October 19. Because "[m]edical decisionmaking is a dynamic process", the government claims that whatever the circumstances before October 19, the possibility remains that changes in the baby's conditions after that date would render the hospital's conduct discriminatory under section 504.

The government's principal argument, however, is that the district court erred in concluding that the parents' refusal to consent to surgery conclusively established the hospital's nondiscrimination and thus insulated the hospital from liability under section 504. In this regard, the government claims, for the first time on appeal, that the requested records were necessary to determine whether the failure of the hospital to seek a state court order overriding the parents' decision and compelling surgery was itself a violation of the nondiscrimination requirements of section 504.

Defendants, on the other hand, together with the various *amici* who support their position, not only defend the district court's decision on its own terms, but also argue that section 504 provides no authority for this action, because (1) medicare and medicaid do not constitute "Federal financial assistance" within the meaning of the statute and (2) congress did not intend that section 504 serve as the basis for federal intervention in medical decisionmaking. In addition, defendants renew their argument that access to the records is barred by New York's physician-patient privilege and the federal constitutional privacy rights of Baby Jane Doe and her parents. Finally, defendants argue that in light of the state court proceedings, this court should deny the federal government access to the records as a matter of equity, comity, and federalism.

## II.

As a preliminary matter, we briefly address the general standards governing a request by an investigating administrative agency such as HHS for the records of an institution such as University Hospital. An administrative agency is entitled to access to information "not plainly incompetent or irrelevant to any lawful purpose of the [agency] in the discharge of [its] duties". *Endicott Johnson Corp. v. Perkins*, 317 U.S. 501, 509 (1943); *see United States v. Morton Salt Co.*, 338 U.S. 632, 641-43 (1950); *Oklahoma Press Publishing Co. v. Walling*, 327 U.S. 186, 208-14 (1946); *SEC v. Brigadoon Scotch Distributing Co.*, 480 F.2d 1047, 1052-55 (2d Cir. 1973), *cert. denied*, 415 U.S. 915 (1974); *see generally* 1 K. Davis, *Administrative Law Treatise* § 4.1 *et seq.* (2d ed. 1978). "So long as an agency establishes that an investiga-

tion 'will be conducted pursuant to a legitimate purpose, that the inquiry may be relevant to the purpose, that the information sought is not already within [its] possession, and that the administrative steps required * * * have been followed,' no showing of probable cause need be made to the district court unless a statute indicates otherwise." *SEC v. Wall Street Transcript Corp.*, 422 F.2d 1371, 1375 (2d Cir.) (citations omitted), *cert. denied*, 398 U.S. 958 (1970). Thus, if the district court meant what at one point it seemed to say—that the government was required to establish some evidence of unlawful discrimination as a condition to obtaining the requested records—it increased the burdens placed on the government by applicable precedents.

At the same time, however, and closer to the thrust of the district court's decision as we read it, an agency is not entitled to information sought in connection with an investigation that "overreaches the authority Congress has given". *Oklahoma Press Publishing Co. v. Walling*, 327 U.S. at 217. As we recognized in *United States v. Cabrini Medical Center*, 639 F.2d 908, 910 (2d Cir. 1981), a case also involving section 504, there is "no point in permitting the Government to institute an investigation with its attendant inconvenience, expense, and annoyance if there is and can be no authority for undertaking it." These concerns are particularly acute in a case like the one at bar, where the demand for information arguably implicates constitutionally protected rights, *cf. Carey v. Population Services International*, 431 U.S. 678, 684-85 (1977); *Whalen v. Roe*, 429 U.S. 589, 598-604 (1977); *Roe v. Wade*, 410 U.S. 113, 152-53 (1973); *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965); *compare Pierce v. Society of Sisters*, 268 U.S. 510,

535 (1925) *with Prince v. Massachusetts*, 321 U.S. 158, 164-71 (1944), and also represents an unprecedented exercise of the agency's investigative powers. Under these circumstances, it is incumbent upon this court to exercise particular care in assuring itself that the subject matter of the investigation is within the agency's statutory jurisdiction. *Federal Election Commission v. Machinists Non-Partisan Political League*, 655 F.2d 380, 385-90 (D.C. Cir.), *cert. denied*, 454 U.S. 897 (1981); *Federal Election Commission v. Florida For Kennedy Committee*, 681 F.2d 1281, 1283-86 (11th Cir. 1982).

Thus, while the philosophical, social, and ethical implications of this case may be far-reaching, the precise issue presented for our review is one of statutory construction: Did congress intend section 504 to reach the conduct HHS seeks to investigate? If the investigation is within the scope of section 504, then HHS is entitled to access to Baby Jane Doe's medical records (unless they are protected from disclosure by some statutory or constitutional provision). On the other hand, if the investigation is beyond the scope of section 504, then the district court properly denied access.

III.

To focus more sharply on this central issue, it is first necessary to examine the theory upon which the government predicates its request for the records under section 504. The theory rests on two premises. First, the government draws a distinction between decisionmaking based on a "bona fide medical judgment", which without definition it concedes to be beyond the reach of section 504, and decisionmaking based solely on an individual's handicap, which it argues is covered by section 504. Second, the government identifies Baby Jane Doe's microcephaly, which

the record indicates will result in severe mental retardation, as the handicapping condition. From these premises, the government reasons that if a newborn infant suffering from spina bifida and hydrocephalus, but not microcephaly, would receive treatment or services that differ from those provided to an infant suffering from all three defects, or alternatively, if the hospital would seek a state court order compelling surgery in the former case, but not in the latter, then a violation of section 504 would have been established. Without the requested records, the government concludes, it is impossible to determine whether any such unlawful discrimination has occurred here, at least after October 19.

A.

In evaluating whether this theory entitles the government to the requested records, we initially assume, without deciding, that the district judge properly determined both that the hospital was a recipient of "Federal financial assistance" within the meaning of the statute, and that the "program or activity" to which the statute applies, if at all, is the entire hospital. Were we forced to confront these unsettled questions, *see United States v. Baylor University Medical Center*, 711 F.2d 38, 40 (5th Cir. 1983), *staying* 564 F. Supp. 1495 (N.D. Tex 1983) ("[w]hether Medicare and Medicaid payments constitute federal financial assistance within the meaning of the Rehabilitation Act is a serious legal question that could have a broad impact upon federal/state relations"); *Grove City College v. Bell*, 687 F.2d 684, 700 (3d Cir. 1982) (under the "program or activity" limitation of Title IX of the Education Amendments of 1972, "[w]here the Federal government furnishes indirect or non-earmarked aid to an institution,

* * * the institution itself must be the 'program' "), *cert. granted*, 103 S.Ct. 1181 (1983), *argued* Nov. 29, 1983, *see* 52 U.S.L.W. 3433 (U.S. Dec. 6, 1983), summary judgment could not properly be granted in favor of either side at this juncture. Far from being undisputed, many of the material facts bearing on those issues have simply not been developed in the record. For example, the record does not reveal the total amount of federal medicare and medicaid funds the hospital has received, directly or indirectly, or more importantly, how those funds are allocated among the various "programs" or "activities" that the hospital may conduct. Indeed, the record is devoid of evidence even as to how the hospital is organized, either internally or as part of a network of state-affiliated institutions.

In support of its position that the hospital's neonatal intensive care unit is the operative "program or activity" (a position which the district court did not adopt), the government did submit an affidavit of an HHS official asserting that University Hospital "received $5,317,912 (gross) in Medicaid reimbursement from October 1, 1982 to November 7, 1983 for one thousand eight hundred and nineteen (1,819) neo-natal billings. The Federal share of this amount is $2,250,285." However, this affidavit alone hardly affords a sufficient basis upon which to determine as a matter of law how the program-specificity requirement of section 504 should be applied here, particularly in light of the potential inconsistency, raised at oral argument, between the positions taken by the federal government in this case and in the *Grove City College* case currently pending in the Supreme Court. As both the opinion of the Third Circuit in *Grove City College*, 687 F.2d at 688-89 & nn. 6-9, and the brief submitted by the government to the Su-

preme Court in challenging that decision, Brief for Respondents at 3-5, *Grove City College v. Bell*, No. 82-792, aptly illustrate in the closely analogous context of Title IX, the issue of program-specificity cannot be properly analyzed in the abstract, but instead requires a concrete set of facts. The same is true with respect to the issue whether an institution that receives medicare or medicaid reimbursements is a recipient of "Federal financial assistance" within the meaning of section 504. *See Bernard B. v. Blue Cross and Blue Shield of Greater New York*, 528 F. Supp. 125, 132 (S.D.N.Y. 1981), *aff'd*, 679 F.2d 7 (2d Cir. 1982) (per curiam).

Given an understandable desire on both sides to resolve this dispute expeditiously, however, we are reluctant to remand the case to the district court for further factual development on these important issues. In the interest of justice, we shall therefore bypass them and proceed directly to the dispositive question whether, assuming the entire hospital is covered by section 504, the statute authorizes the type of investigation initiated here.

B.

While the question whether section 504 authorizes HHS to investigate medical treatment decisions involving defective newborn infants is technically one of first impression, we do not write on an entirely clean slate. The regulatory history of the statute reveals that the question has already received considerable attention.

In its original notice of intent to issue proposed rules under section 504, published in May 1976, HHS's predecessor, the Department of Health, Education and Welfare (HEW), requested comment on

fifteen "critical issues", *see* 41 Fed. Reg. 29548, including "[w]hether a regulation should contain provisions concerning [institutionalized] patients' rights to receive or refuse treatment * * *". 41 Fed. Reg. 20296 at 20297. Subsequently, in a July 1976 notice of proposed rulemaking, HEW indicated that it had received several comments urging "that the department did *not* have authority to regulate in this area" (emphasis added). 41 Fed. Reg. 29548 at 29559. HEW embraced this position, announcing that "[t]he Secretary is of the opinion that to promulgate rules on these subjects is beyond the authority of section 504." *Id.*

This limited view of the scope of section 504 was reflected in the first set of proposed regulations promulgated by HEW. The applicable provision, the proposed version of 45 C.F.R. § 84.52, emphasized the "[*a*]*vailability of services*" to handicapped persons and required that services be made "accessible" through use of methods such as "making house calls, referring patients, arranging to meet patients in accessible facilities, and modifying facilities." 41 Fed. Reg. at 29567 (emphasis in original).

Notwithstanding comments that its proposed health services regulation "lacks specificity", 42 Fed. Reg. at 22693, in its final section 504 regulations, issued in May 1977, HEW created a general "Health, welfare, and other social services" provision, 45 C.F.R. § 84.52, which emphasizes "the basic requirement of equal opportunity to receive benefits * * *". 45 C.F.R., Part 84, Appendix A, ¶ 36. The agency did, however, also offer more specific guidance on the nature of the nondiscrimination requirement imposed by the regulation:

> One common misconception about the regulation is that it would require specialized hospitals and

other health care providers to treat all handicapped persons. The regulation makes no such requirement. Thus, a burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

It was not until five years later that HHS first took the position that section 504 made it unlawful for hospitals receiving "Federal financial assistance" to withhold nutrition, or medical, or surgical treatment from handicapped infants if required to correct a life-threatening condition. *See American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 397 (D.D.C. 1983) (describing the circumstances leading to this shift in agency policy). This new position was reflected in a "notice * * * to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973", dated May 18, 1982 and published on June 16, 1982. 47 Fed. Reg. 26027. In the notice, HHS "recognize[d] that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused." *Id.* Nevertheless, referring to 45 C.F.R. § 84.4(b)(1)(v), which provides that a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person, the notice admonished that:

- Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.

> • Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

*Id.*

Nearly a year after this notice was published, in March 1983, HHS issued an interim final rule "to meet the exigent needs that can arise when a handicapped infant is discriminatorily denied food or other medical care." 48 Fed. Reg. 9630. This "novel and far-reaching" regulation, *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 397, would have required "each recipient that provides covered health services to infants" to display posters in conspicuous places "in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery" declaring that "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW". 48 Fed. Reg. at 9631, *amending* 45 C.F.R. § 84.61. The interim regulation also established a confidential "Handicapped Infant Hotline", "[a]vailable 24 hours a day", which "[*a*]*ny person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact*" (emphasis in original). *Id.* Further, the regulation stated that the required access to records "shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual." *Id.*

The preamble to the interim rule made clear that HHS believed it could conduct immediate investigations and make immediate referrals to the Depart-

ment of Justice for appropriate legal action. 48 Fed. Reg. at 9631. However, without eschewing "a vigorous federal role in enforcing the federal civil rights at issue", it also indicated that "[t]he Secretary intends to rely heavily on the voluntary cooperation of State and local agencies, which are closest to the scene of violations, and which have traditionally played the key role in the investigation of complaints of child abuse and neglect." *Id.* at 9630.

On April 14, 1983, this interim final rule was struck down by the United States District Court for the District of Columbia. *American Academy of Pediatrics v. Heckler, supra.* In a thorough and informative opinion, Judge Gesell held that the regulation failed to satisfy the requirements of the Administrative Procedure Act, 5 U.S.C. § 551 *et seq.* (1982), in two respects. First, since the rulemaking record indicated the regulation was a product of "haste and inexperience", 561 F. Supp. at 400, and that many relevant factors, including the scope of section 504, were not considered, the court ruled that the interim final rule was arbitrary and capricious under 5 U.S.C. § 706(2)(A). As the court explained:

> Government intervention into the difficult medical and human decisions that must be made in the delivery rooms and newborn intensive care units of our hospitals involves a profound change in the manner in which these decisions affecting the quality of life are made. Any intervention by an agency of the Federal Government should obviously reflect caution and sensitivity, given the present absence of a clear congressional directive.

561 F. Supp. at 403.

Second, the court ruled that the regulation was invalid due to the secretary's failure to follow the pro-

cedural requirements of 5 U.S.C. § 553(b) and (d). In this regard, Judge Gesell reasoned that the interim final rule could not properly be viewed as a restatement of preexisting law or policy, as the government had alleged:

> As [HHS's] counsel acknowledged in argument, the regulation is intended, among other things, to change the course of medical decisionmaking in these cases by eliminating the parents' right to refuse to consent to life-sustaining treatment of their defective newborn. Moreover, the regulation provides for an intrusive on-premises enforcement mechanism that can be triggered by a simple anonymous call. Thus it clearly is more than a "clarification or explanation of an existing rule or statute" and affects substantive rights.

561 F. Supp. at 401 (footnote and citation omitted).

Following this decision, on July 5, 1983 HHS published a proposed rule in which the notice requirement was slightly revised, and a provision was added declaring that "* * * each recipient State child protective services agency shall establish and maintain written methods of administration and procedures to assure that the agency utilizes its full authority pursuant to State law to prevent instances of medical neglect of handicapped infants." 48 Fed. Reg. 30846 at 30851. In the appendix to the proposed rule, HHS listed several examples of decisions that would, in its view, constitute violations of section 504. These included:

> (3) Denial of treatment for medically correctable physical anomalies in children born with

> Spina Bifida, when such denial is based on anticipated mental impairment, paralysis, or incontinence of such child, rather than on reasonable medical judgments that treatment would be futile or too unlikely of success given complications in the particular case.

*Id.* at 30852.

More recently, on January 12, 1984, after oral argument of this appeal, HHS issued its "final rules on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants." 49 Fed. Reg. 1622. These final rules modified the proposed rules in several major respects. *Id.* For example, HHS adopted the recommendation of several commenters that the federal government encourage, but not require, hospitals to establish Infant Care Review Committees "to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases." 45 C.F.R. § 84.55(a), 49 Fed. Reg. 1651; *see id.* at 1623-25. These committees are not, however, designed to be substitutes for mechanisms to enforce section 504. *Id.* at 1624.

Under the final rules, the notice requirement is also significantly modified. Among other things, the final rules require only that the notice be posted

> at location(s) where nurses and other medical professionals who are engaged in providing health care and related services to infants will see it. To the extent it does not impair accomplishment of the requirement that copies of the notice be posted where such personnel will see it,

> the notice need not be posted in area(s) where parents of infant patients will see it.

45 C.F.R. § 84.55(b)(2), 49 Fed. Reg. 1651.

In sum, the regulatory history of section 504 is inconclusive. HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW. Notwithstanding HHS's claims to the contrary, *see* 49 Fed. Reg. at 1635, the current view also represents something of a retreat from the interpretation HHS adopted just last year. In determining whether congress intended section 504 to apply to treatment decisions involving defective newborn infants, we therefore lack the benefit of an administering agency's longstanding, consistent interpretation to which we otherwise might have looked for guidance. *See Frank Diehl Farms v. Secretary of Labor*, 696 F.2d 1325, 1329-31 (11th Cir. 1983); *see also American Federation of Government Employees v. Federal Labor Relations Authority*, 712 F.2d 640, 643 n. 17 (D.C. Cir. 1983); *cf. United States v. Clark*, 454 U.S. 555, 565 (1982); *see generally* 2 K. Davis, *Administrative Law Treatise* § 7.14 (2d ed. 1979).

C.

With this unsettled regulatory background in mind, we turn to the statutory language, which is fundamental to any issue of statutory construction. *See North Haven Board of Education v. Bell*, 456 U.S. 512, 520 (1982). Section 504 provides in pertinent part as follows:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be

> denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

Under 29 U.S.C. § 706(7)(B), "the term 'handicapped individual' means * * * any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

The initial inquiry is whether Baby Jane Doe is properly considered a "handicapped individual" within the meaning of section 706(7). The issue is not as simple as it first seems. While there can be no question that Baby Jane Doe currently suffers from "physical or mental impairments", *see* 45 C.F.R. § 84.3(j)(2)(i), it is less clear whether these impairments substantially limit "major life activities".

Defendants and some of the *amici* contend that the phrase "major life activities", undefined in the Rehabilitation Act, should be interpreted to exclude newborn infants from the coverage of section 504. In support, they rely on congress's declaration in section 122(a)(1) of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, Pub. L. No. 95-602, 92 Stat. 2984, codified at 29 U.S.C. § 701, that the purpose of the Rehabilitation Act "is to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living." This purpose, they assert, is inapplicable to newborn infants, since: "By definition, such infants cannot be eligible for programs of employment, vocational rehabilitation or training. Indeed, no program of independent living can be seriously comprehended for

any infant, let alone an infant who has a life-threatening disorder."

Further support for the view that section 504 does not apply to newborn infants can be found in the regulations HHS inherited from HEW. Under 45 C.F.R. § 84.3(j)(2)(ii), " 'Major life activities' means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." With or without corrective surgery, Baby Jane Doe's impairments unquestionably will substantially limit some of these functions in the future. However, the same cannot necessarily be said of the present, since newborn infants simply cannot perform many of these representative functions.

Notwithstanding this ambiguity in the phrase "major life activities", we hold that Baby Jane Doe falls within the definition of a "handicapped individual" in section 706(7)(B). The record indicates that Baby Jane Doe's rectal, bladder, leg, and sensory functions are all presently impaired. Further, the record suggests that, with or without corrective surgery, Baby Jane Doe will experience severe mental retardation for however long she lives. Absent any explicit indication in the statute or regulations that "major life activities" should be defined only with reference to adults, under these circumstances it would defy common sense to rule that she is not presently *regarded* as handicapped under section 706(7)(B)(iii).

Moreover, while congress may not have had handicapped children squarely in mind when it first formulated the definition of a "handicapped individual" in section 706(7)(B) in 1974, *see infra*, it has subsequently evinced its intent that such children re-

ceive at least some of the benefits of the Rehabilitation Act. In 1978, as part of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, congress authorized the Director of the Interagency Committee on Handicapped Research to make grants for research into "services for preschool age handicapped children." Pub. L. No. 95-602, § 111, 92 Stat. 2967, codified at 29 U.S.C. § 762(11). The fact that congress recognized the needs of preschool age handicapped children in section 762(11) undercuts defendants' argument that, since the declared purpose of the entire Rehabilitation Act set forth in section 701 focuses on activities available only to adults, the "major life activities" referred to in section 706(7) should be similarly limited.

Having determined that Baby Jane Doe is a "handicapped individual" under section 706(7)(B), we next consider whether she possibly can be considered an "otherwise qualified" handicapped individual or to have been "subjected to discrimination" under section 504. These two issues are intertwined.

The leading cases construing the "otherwise qualified" criterion of section 504 have involved allegedly discriminatory denials of admission to certain educational programs. *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979); *Doe v. New York University*, 666 F.2d 761 (2d Cir. 1981). In that context, this court in *Doe v. New York University* recognized that:

> * * * it is now clear that [the phrase "otherwise qualified handicapped individual"] refers to a person who is qualified *in spite of* her handicap and that an institution is not required to disregard the disabilities of a handicapped applicant,

> provided the handicap is relevant to reasonable qualifications for acceptance, or to make substantial modifications in its reasonable standards or program to accommodate handicapped individuals but may take an applicant's handicap into consideration, along with all other relevant factors, in determining whether she is qualified for admission.

*Id.* at 775 (emphasis in original). *Cf.* 45 C.F.R. 84.3(k).

*Doe* establishes that section 504 prohibits discrimination against a handicapped individual only where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question. As defendants here point out, however, where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to, the need for services. Defendants thus argue, and with some force, that the "otherwise qualified" criterion of section 504 cannot be meaningfully applied to a medical treatment decision. Similarly, defendants argue that it would be pointless to inquire whether a patient who was affected by a medical treatment decision was, "solely by reason of his handicap, * * * subjected to discrimination".

The government's answer to both these arguments is that Baby Jane Doe can be viewed as suffering from not one, but multiple handicaps. Indeed, the crux of the government's case is that her microcephaly is the operative handicap, and that the requested records are necessary to determine whether she has been discriminated against solely for that reason.

Despite its superficial logic, the government's theory is flawed in at least two respects. First, the government's view of "otherwise qualified" is divorced from

the statutory language. As the mainstream of cases under section 504 exemplifies, the phrase "otherwise qualified" is geared toward relatively static programs or activities such as education, *e.g.*, *Southeastern Community College v. Davis*, 442 U.S. 397; *Doe v. New York University*, 666 F.2d 761, employment, *e.g.*, *Prewitt v. United States Postal Service*, 662 F.2d 292 (5th Cir. 1981); *Simon v. St. Louis County*, 497 F. Supp. 141, *aff'd in part, rev'd in part on other grounds*, 656 F.2d 316 (8th Cir. 1981), *cert. denied*, 102 S.Ct. 1485 (1982), and transportation systems, *e.g.*, *Dopico v. Goldschmidt*, 687 F.2d 644, 652-53 (2d Cir. 1982). As a result, the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning. In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents. If congress intended section 504 to apply in this manner, it chose strange language indeed. *See American Trucking Associations, Inc. v. United States*, 602 F.2d 444, 449-50 (D.C. Cir.), *cert. denied*, 444 U.S. 991 (1979) (statutory language "should be given its plain, obvious and rational meaning").

Second, in arguing that Baby Jane may have been "subjected to discrimination" the government has taken an oversimplified view of the medical decision-making process. Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily

by the dissent, breaks down. Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment", however that phrase might be defined. Before ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute.

The legislative history, moreover, indicates that congress never contemplated that section 504 would apply to treatment decisions of this nature. The Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355, was a comprehensive legislative package that was considered and passed by congress three times before it was finally signed into law by President Nixon. S. Rep. No. 318, 93d Cong., 1st Sess., *reprinted in* [1973] U.S. Code Cong. & Ad. News 2076, 2086-90. Each version of the legislation approved by congress contained a provision prohibiting discrimination against the handicapped by federal grantees. *Id.* at 2078-82; *see Le Strange v. Consolidated Rail Corp.*, 687 F.2d 767, 772 (3d Cir. 1982), *cert. granted*, 103 S.Ct. 1181 (1983), *argued* Nov. 29, 1983, *see* 52 U.S.L.W. 3393 (U.S. Nov. 22, 1983). However, this provision, which had been closely patterned after Title VI of the Civil Rights Act of 1964 and Title IX of the Education Amendments of 1972, *see* S. Rep. No. 1297, 93d Cong., 2d Sess., *reprinted in* [1974] U.S. Code Cong. & Ad. News 6373, 6390-91, was never a matter of controversy. Consequently, there is little discussion of it in the volumes of legislative history that were generated. *See Le Strange v. Consolidated Rail Corp., supra.*

The senate committee report that introduced the provision simply stated "[t]he bill further proclaims a policy of nondiscrimination against otherwise qualified handicapped individuals with respect to participation in or access to any program which is in receipt of Federal financial assistance." S. Rep. No. 1135, 92d Cong., 2d Sess. 49, *see* 118 Cong. Rec. 32294. Examples of programs that the provision was designed to cover that were identified on the floor of the senate included housing and employment. *See* 119 Cong. Rec. 5882 (remarks of Sen. Cranston).

Interestingly, the only consideration of medical issues that occurred in connection with the 1973 legislation did not involve the nondiscrimination provision that would eventually become section 504. In the first two versions of the legislation, congress had created several categorical programs to benefit target populations including those with end-stage renal disease and those with severe spinal cord injuries. In vetoing each of the first two versions of the Rehabilitation Act, President Nixon took issue with what he perceived to be congress's attempts to extend what was essentially a vocational program into the medical realm. *See* 118 Cong. Rec. 5880 (first veto memorandum); 119 Cong. Rec. 24570 (second veto memorandum). Ultimately, congress was forced to back down, *see* 119 Cong. Rec. 24566 (remarks of Sen. Cranston), and the final version of the 1973 legislation authorized research projects rather than categorical programs to benefit the target populations with which congress was concerned.

Since the primary purpose of the 1973 legislation was to extend and expand the 53-year old federal-state vocational rehabilitation program, it is not surprising that congress initially defined the phrase "handicapped individual" in terms of employment:

> The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services * * *.

Pub. L. No. 93-112, § 7(6), 87 Stat. 355, 361.

However, because "[i]t was clearly the intent of the Congress in adopting section 503 (affirmative action) and section 504 (nondiscrimination) that the term 'handicapped individual' in those sections was not to be narrowly limited to employment (in the case of section 504), nor to the individual's potential benefit from vocational rehabilitation services under titles I and III (in the case of both sections 503 and 504) of the Act", S. Rep. No. 1297, 93d Cong., 2d Sess., *reprinted in* [1974] U.S. Code Cong. & Ad. News 6373, 6388, congress expanded the definition to its current version, focusing on "major life activities", in the Rehabilitation Act Amendments of 1974, Pub. L. No. 93-516, § 111(a), 88 Stat. 1619. As the senate report accompanying the 1974 amendments elaborated:

> Thus, it was not intended that an employer-government contractor should condition its hiring of handicapped individuals under an affirmative action plan on such individuals' having benefitted, or having a reasonable expectation of benefitting, from vocational rehabilitation services. Similarly, a test of discrimination against a handicapped individual under section 504 should not be couched either in terms of whether such individual's disability is a handicap to employment, or whether such individual can reasonably be ex-

pected to benefit, in terms of employment, from vocational rehabilitation services. Such a test is irrelevant to the many forms of potential discrimination covered by section 504.

Section 504 was enacted to prevent discrimination against all handicapped individuals, regardless of their need for, or ability to benefit from, vocational rehabilitation services, in relation to Federal assistance in employment, housing, transportation, education, health services, or any other Federally-aided programs. Examples of handicapped individuals who may suffer discrimination in receipt of Federally-assisted services but who may have been unintentionally excluded from the protection of section 504 by the references to enhanced employability in section 7(6) are as follows: physically or mentally handicapped children who may be denied admission to Federally-supported school systems on the basis of their handicap; handicapped persons who may be denied admission to Federally-assisted nursing homes on the basis of their handicap; those persons whose handicap is so severe that employment is not feasible but who may be denied the benefits of a wide range of Federal programs; and those persons whose vocational rehabilitation is complete but who may nevertheless be discriminated against in certain Federally-assisted activities.

S. Rep. No. 1297, *supra* at 6388-89.

This passage provides the best clue to congressional intent regarding section 504's coverage of "health services". As Judge Gesell noted in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 401:

> The legislative history * * * [on this subject] focuses on discrimination against adults and older children and denial of access to federal programs. As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking, nor were representatives of parents or spokesmen for religious beliefs that would be affected heard.

The post-enactment legislative history also indicates both that congress was primarily concerned with affording the handicapped access to federally-funded programs and activities, and that congress never envisioned that HEW (or HHS) would attempt to apply section 504 to treatment decisions. On April 28, 1977, the day the original set of final section 504 regulations were promulgated by HEW, then Secretary Califano sent congress an explanatory letter. After observing that the regulation "calls for dramatic changes in the actions and attitudes of institutions and individuals who are recipients of HEW funds", and "opens a new era of civil rights in America", Secretary Califano stated that "[i]n light of the limited legislative history, I think it especially important that Congress evaluate the regulation, and the implementation process, to ensure that they conform to the will of Congress." (letter reprinted in Hearings Before the Subcommittee on Select Education of the Committee on Education and Labor of the House of Representatives, 95th Cong., 1st Sess. 76 (hereinafter referred to as "Oversight Hearings")).

Thereafter, the House Subcommittee on Select Education conducted oversight hearings on the section 504 regulations in September 1977. During these hearings, the subcommittee heard testimony covering a wide range of topics from witnesses representing the federal government, state governments, education agencies, and organizations serving handicapped people. Throughout the hearings, the issue of program accessibility was a recurrent theme. *See* Oversight Hearings at 1 (remarks of Congressman Brademas) ("Central to the implementation of these regulations must be the realization that what handicapped people want is access to programs"); 36-37 (remarks of Thomas P. Carroll); 246 (remarks of Debbie Kaplan); 248 (remarks of Ralph Hotchkiss); 295, 358-59, 361 (remarks of David S. Tatel).

On the other hand, although several witnesses echoed Secretary Califano's remark that the newly-issued regulations ushered in a "new era" of civil rights for handicapped citizens, *see* Oversight Hearings at 31 (remarks of Thomas P. Carrol); 337 (remarks of David S. Tatel), and another observed that "many are the issues which cry out for resolution", *id.* at 217 (remarks of James Gashel), at no point did any witness even remotely suggest that section 504 could or would be applied to treatment decisions involving defective newborn infants. Instead, those witnesses who addressed the legal, as opposed to the fiscal, issues raised by HEW's section 504 regulations, including the director of HEW's Office of Civil Rights (OCR), David S. Tatel, *see id.* at 290-368, focused on subjects such as OCR's complaint backlog, *id.* at 218-20 (remarks of James Gashel), and whether attorneys' fees should be made available in private enforcement actions. *Id.* at 2125 (remarks of

Frank G. Bower); 245 (remarks of Debbie Kaplan); 257-63 (remarks of Daniel Yohalem).

We are aware, of course, that "[w]here the words and purpose of a statute plainly apply to a particular situation, * * * the fact that the specific application of the statute never occurred to Congress does not bar us from holding that the situation falls within the statute's coverage." *United States v. Jones*, 607 F.2d 269, 273 (9th Cir. 1979), *cert. denied*, 444 U.S. 1085 (1980); *see Affetto v. TRW, Inc.*, 691 F.2d 357, 362 (7th Cir. 1982); *United States v. Bates*, 617 F.2d 585, 587 n. 7 (10th Cir. 1980); *Portland Cement Association v. Ruckelshaus*, 486 F.2d 375, 380 (D.C. Cir. 1973), *cert. denied*, 417 U.S. 921 (1974); *see also Jefferson County Pharmaceutical Association, Inc. v. Abbott Laboratories*, 103 S.Ct. 1011, 1017 n. 18 (citing cases). Here, however, the government's theory not only strains the statutory language but also goes well beyond congress's overriding concern with guaranteeing handicapped individuals access to programs or activities receiving federal financial assistance. Further, the situation in question is dramatically different in kind, not just in degree, from the applications of section 504 discussed in the legislative history. Under these circumstances, the failure of congress to focus on treatment decisions involving defective newborn infants strikes a telling blow to the government's position.

This void in the legislative history is conspicuous for another reason. Prior to the enactment of the Rehabilitation Act, congress had passed a number of measures limiting federal involvement in medical treatment decisions. For example, the very first section of the medicare law, first enacted in 1965, Pub. L. No. 89-97, § 102(a), 79 Stat. 291, codified at 42

U.S.C. § 1395, ironically one of the laws under which the government purports to exercise jurisdiction in this case, provides that "[n]othing in this subchapter shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided * * *". Similarly, when it enacted the Professional Standards Review Organization (PSRO) provisions of the Social Security Act in 1972, Pub. L. No. 92-603, § 249F (b), 86 Stat. 1429, codified at 42 U.S.C. § 1320c *et seq.*, congress reiterated its view that determinations regarding the quality and appropriateness of medical treatment should not be undertaken by federal officials. *See* S. Rep. No. 1230, 92nd Cong., 2d Sess. 256-58 (1972); *see also Public Citizen Health Research Group v. HEW*, 668 F.2d 537, 542 (D.C. Cir. 1981).

In view of this consistent congressional policy against the involvement of federal personnel in medical treatment decisions, we cannot presume that congress intended to repeal its earlier announcements in the absence of clear evidence of congressional intent to do so. *See Tennessee Valley Authority v. Hill*, 437 U.S. 153, 189-93 (1978) (citing cases). As has already been seen there is no such clear expression of congressional intent in either the language or legislative history of section 504.

Along the same lines, we cannot presume that by enacting section 504, congress intended the federal government to enter the field of child care, which, as HHS has recently acknowledged, has traditionally been occupied by the states. *See* 49 Fed. Reg. 1626-27, 1629-31; 48 Fed. Reg. 9630. Had congress intended to displace state police power functions, it surely would have made that intention explicit.

Finally, case law construing section 504, while not directly on point, also suggests that the government's new interpretation of the statute exceeds the authority conferred by congress. In *Southeastern Community College v. Davis*, 442 U.S. 397 (1979), the Supreme Court emphasized that "[t]he language and structure of the Rehabilitation Act of 1973 reflect the recognition by Congress of the distinction between the evenhanded treatment of qualified handicapped persons and affirmative efforts to overcome the disabilities caused by handicaps." *Id.* at 410. The Court concluded that "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds." *Id.* at 411. *See American Public Transit Association v. Lewis*, 655 F.2d 1272 (D.C. Cir. 1981), *cf. Dopico v. Goldschmidt*, 687 F.2d 644 (2d Cir. 1982).

In the present case, Baby Jane Doe has been treated in an evenhanded maner at least to the extent that the hospital has always been and remains willing to perform the dual, corrective surgeries if her parents would consent. Requiring the hospital either to undertake surgery notwithstanding the parents' decision or alternatively, to petition the state court to override the parents' decision, would impose a particularly onerous affirmative action burden upon the hospital. *Cf. American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 402 ("section 504 was never intended by Congress to be applied blindly and without any consideration of the burdens and intrusions that might result").

## IV.

We have been called upon on this appeal "to determine the applicability of a statute where the language

of the statute does not make crystal clear its intended scope." *Allen v. State Board of Elections*, 393 U.S. 544, 570 (1969). As the Supreme Court stated in *Allen*, "[i]n all such cases we are compelled to resort to the legislative history to determine whether, in light of the articulated purposes of the legislation, Congress intended that the statute apply to the particular case[] in question." *Id*; *see Montana Power Co. v. Federal Power Commission*, 445 F.2d 739, 746 (D.C. Cir. 1970) (*en banc*), *cert. denied*, 400 U.S. 1013 (1971). Our review of the legislative history has shown that congress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants when the statute was enacted in 1973, when it was amended in 1974, or at any subsequent time. Further, neither the articulated purposes of the statute, which concern access and admission to federally-funded programs and activities for otherwise qualified handicapped individuals, nor any fair and reasonable projections of those purposes, *see Montana Power Co. v. Federal Power Commission*, *supra*, nor the applicable case law interpreting the statute, support the far-reaching position advanced by the government in this case.

"[G]iven the present absence of a clear congressional directive", *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 403, we agree with Judge Gesell that "[a]ny intervention by an agency of the Federal Government should obviously reflect caution and sensitivity". *Id.* We go one step further, however, and hold that under these circumstances it is congress, rather than an executive agency, that must weigh the competing interests at stake in this context in the first instance. Until congress has spoken, it

would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit.

The judgment of the district court is therefore affirmed.

WINTER, *Circuit Judge, dissenting*:

Since I believe that Section 504 applies to the provision of medical services to handicapped infants, I respectfully dissent. I would reverse and remand for further consideration of whether the kinds of federal financial assistance received by the defendant hospital subject the hospital to the commands of Section 504 in the case of the infant in question.

## I

Section 504 provides that

> [n]o otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

29 U.S.C. § 794. It thus states with as much clarity as is reasonably possible that in some circumstances recipients of federal financial assistance may not differentiate between individuals on grounds that one or more is handicapped. The only ambiguity relevant to the present case, I respectfully suggest, is whether the hospital is such a recipient with regard to its obligations to Baby Jane Doe and not whether Section 504 includes the provision of medical services to handicapped infants.

Although modern courts frequently rely upon legislative history to reach results at odds with the seemingly plain language of a statute, only the most compelling reasons should induce a court to override statutory language because the legislative history is silent on a particular point. Such compelling circumstances might exist in the present case if Congress

had no reason to address the questions at hand when it enacted Section 504. It hardly needs stating that the underlying issues brim with political and moral controversy and portend to extend the hand of the federal government into matters traditionally governed by an interaction of parental judgment and state authority. Were I able to conclude that Congress had no reason to address these issues in its consideration of Section 504, I would concur with the majority on the grounds that specific consideration by the Congress of this political and moral minefield would be appropriate before applying the statute as written.

However, such a conclusion is untenable since Section 504 is no first step into a hitherto uncharted legal wilderness. As the Senate Report stated:

> Section 504 was patterned after, and is almost identical to, the antidiscrimination language of section 601 of the Civil Rights Act of 1964, 42 U.S.C. 2000d-1 (relating to race, color, or national origin), and section 901 of the Education Amendments of 1972, 42 U.S.C. 1683 (relating to sex). The section therefore constitutes the establishment of a broad government policy that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap.

S. Rep. No. 1297, 93d Cong., 2d Sess., *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6390. Section 504 was thus enacted against a background of well understood law which was explici ly designated as a guide to interpretation. Congress was persuaded that a handicapped condition is analogous to race and that, so far as the administration of federal fi-

nancial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race.

Once Section 504's legislative heritage is acknowledged, the "void" in the legislative history is eliminated and the many issues raised by defendants with regard to medical decisions, parental judgments and state authority simply evaporate. The government has never taken the position that it is entitled to override a medical judgment. Its position rather is that it is entitled under Section 504 to inquire whether a judgment in question is a *bona fide* medical judgment. While the majority professes uncertainty as to what that means, application of the analogy to race eliminates all doubt. A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. Finally, once the legislative analogy to race is acknowledged, the intrusion on state authority becomes insignificant.

The logic of the government's position on these aspects of the case is thus about as flawless as a legal argument can be. Any doubt must stem not from a deficiency in the argument based on the analogy to Title VI of the Civil Rights Act but from a disagreement as to whether a handicapped condition is fully analogous to race. *See American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402 (D.D.C. 1983). Whether that doubt is justified or

not, however, courts are not the proper fora in which the reasonableness of the analogy to race is to be judged.

Selective refusals to be guided by precedents under Title VI of the Civil Rights Act are likely to lead to an incoherent body of interpretative law under Section 504. Ambiguity pervades the majority opinion as to exactly which services and which handicapped persons are excluded from the statute. All one can know for certain is that some medical services may be denied to some handicapped persons, without running afoul of Section 504. The majority even implies, *inter alia*, that Section 504 may not apply at all to the provision of medical services, since such services are inseparable from treatment decisions. This is in the face of the explicit statement of the Senate Report that it "was enacted to prevent discrimination against all handicapped individuals . . . in . . . health services," S. Rep. No. 1297, *supra*, *reprinted in* 1974 U.S. Code Cong. & Ad. News at 6388. If that interpretation stands, the handicapped will be deprived of a fairly won political victory and exposed to the possibility of future decisions excluding other services from coverage by Section 504. On the other hand, the majority opinion also implies that a narrower holding may be intended and that only certain kinds of handicapped persons are excluded. If that interpretation stands, then the federal courts may be forced to resolve individually each of these human tragedies and moral dilemmas. It was Judge Gesell's prediction in *American Academy of Pediatrics*, the precedent drawn upon so heavily by the majority, that Section 504 will require line-drawing in individual cases between the extremes of a failure to provide services to a mildly

handicapped child and a failure to use heroic measures to prolong for a period of time the life of an infant who has no hope of achieving even minimal consciousness. 561 F. Supp. at 402. Such a reading of Section 504, however, intrudes quite as profoundly upon medical decisions, parental judgments and state authority as the interpretation proffered by the government and thus undermines the reasoning of the majority.

Also, I would respectfully suggest that we act outside our legitimate area of authority in declining to follow the path staked out by Title VI of the Civil Rights Act. Congress did not adopt the analogy to race merely as a legislative means to a policy goal but was persuaded and politically energized by the view that the analogy was correct. A judicial failure to follow the analogy where it leads is an outright disagreement with Congress' judgment and an unconstitutional act in itself.

Finally, we facilitate the democratic legislative process by applying the analogy to race as adopted by the Congress. A political temptation to avoid confrontations with issues of moral or prudential controversy is an inevitable aspect of legislative deliberations. If courts are perceived as ready to "correct" overbroad legislation, Congress will find it ever more tempting to avoid its responsibility to address and resolve the highly delicate issues which may lurk in seemingly unobjectionable legislative proposals. Rhetorical flourishes will be substituted for statutory precision and "voids" in legislative histories will be ever more frequent. This is particularly so in cases involving legislative analogies to race. The moral and legal successes of the civil rights movement have prompted

many groups to seek legislation which puts a particular characteristic or condition on a legal par with race. So long as the courts are perceived to stand ready to consider tempering such legislation where it leads to controversial results, the path of least political resistance will always be for the Congress to avoid serious consideration of the actual consequences of legislating particular analogies to race. Only an apprehension that such legislative analogies will be enforced by courts as written can provide a counter incentive to induce Congress to address its legislative responsibilities.

II

I agree with that portion of the discussion in Part II A of Judge Pratt's opinion which concludes that we cannot determine on the present record whether the defendant hospital is a recipient of "financial federal assistance" within the meaning of Section 504 and whether the "program or activity" to which that section applies is the entire hospital. I would, therefore, reverse and remand so that the record can be amplified. In light of the pendency of *Grove City College v. Bell*, 687 F.2d 684 (3rd Cir. 1982), *cert. granted*, 103 S. Ct. 1181 (1983), argued Nov. 29, 1983, *see* 52 U.S.L.W. 3433 (U.S. Dec. 6, 1983) and in view of the majority's decision, further discussion of this issue by me would be superfluous.

For the reasons stated above, I dissent.

APPENDIX C

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

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83 Civ. 2638-CLB

AMERICAN HOSPITAL ASSOCIATION, ETC.,
HOSPITAL ASSOCIATION OF NEW YORK STATE, ETC.
and STRONG MEMORIAL HOSPITAL OF THE
UNIVERSITY OF ROCHESTER, PLAINTIFFS

*—against—*

MARGARET M. HECKLER, Secretary,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES,
DEFENDANT

---

84 Civ. 1724-CLB

AMERICAN MEDICAL ASSOCIATION, ET AL., PLAINTIFFS

*—against—*

MARGARET M. HECKLER, Secretary,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES,
DEFENDANT

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MEMORANDUM AND ORDER

*Brieant, J.*

There being no material facts in dispute, the motions by plaintiffs for summary judgment are granted.

See transcripts of hearings on March 23, 1984 and April 9, 1984.

This consolidated case is directly controlled by the decision of our Court of Appeals in *United States* v. *University Hospital*, No. 83-6343 (2d Cir. February 23, 1984) (slip op.), *motion for rehearing en banc denied*, May 17, 1984.

The final regulations challenged by plaintiffs in this consolidated action, 45 C.F.R. § 84.55(b)-(e), 49 Fed. Reg. 1622, *et seq.* (January 12, 1984), were promulgated solely under the purported authority of § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 974, see 49 Fed. Reg. at 1622. Accordingly, in light of *University Hospital*, *supra*, they are invalid, unlawful and must be set aside pursuant to the Administrative Procedure Act, 5 U.S.C. § 706(2)(C), because promulgated without statutory authority.

In light of the denial of reconsideration *en banc* of *University Hospital*, *supra*, this Court finds it unnecessary to reach the constitutional issues raised by plaintiffs. Nor need the Court now consider the effect of the Supreme Court's decision in *Grove City College* v. *Bell*, —— U.S. ——, 52 U.S.L.W. 4283 (February 28, 1984), decided subsequent in time to the panel opinion in *University Hospital*, *supra*. See our Memorandum and Order dated May 11, 1984.

Settle final declaratory judgment on five (5) days notice.

So Ordered.

Dated: New York, New York
May 23, 1984

/s/ Charles L. Brieant
CHARLES L. BRIEANT
U.S.D.J.

## APPENDIX D

## UNITED STATES DISTRICT COURT
## SOUTHERN DISTRICT OF NEW YORK

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83 Civ. 2638-CLB

AMERICAN HOSPITAL ASSOCIATION, ET AL., PLAINTIFFS

*—against—*

MARGARET M. HECKLER, DEFENDANT

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84 Civ. 1724-CLB

AMERICAN MEDICAL ASSOCIATION, ET AL., PLAINTIFFS

*—against—*

MARGARET M. HECKLER, DEFENDANT

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## FINAL JUDGMENT

*Brieant, J.*

WHEREAS, Plaintiffs have moved for summary judgment on Count I of their Complaint which seeks declaratory and permanent injunctive relief against Defendant's final regulations on "Procedures and Guidelines Relating to Health Care for Handicapped Infants," 45 C.F.R. §§ 84.55(b)-(e), 49 Fed. Reg. 1622 (January 12, 1984) [hereinafter the "Final Regulation"], and against any other actions by Defendant to investigate and regulate treatment involving impaired newborn infants taken under authority

of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, including currently pending investigation and other enforcement actions; and

WHEREAS, the Court has granted Plaintiffs' motion for summary judgment by Memorandum and Order dated May 23, 1984 because, under the decision in *United States* v. *University Hospital*, 729 F.2d 144 (2d Cir. 1984), Defendant has no authority under Section 504 to investigate or to otherwise regulate treatment decisions involving impaired newborn infants;

NOW, it is hereby ORDERED that:

1. The Final Regulation and all actions implementing it are declared invalid and unlawful as exceeding the scope of Defendant's authority under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, and thus have no further force or effect.

2. Any other actions of Defendant to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions, are declared invalid and unlawful as exceeding the scope of Defendant's authority under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, and thus have no further force or effect.

3. Defendant, her officers, agents, employees and attorneys are permanently enjoined from any further implementation of the Final Regulation with respect to "any program or activity receiving Federal financial assistance." *See* 29 U.S.C. § 794 and 29 U.S.C. § 706(14).

4. Defendant, her officers, agents, employees and attorneys are also permanently enjoined from continuing or undertaking any other actions to investi-

gate or regulate treatment decisions involving impaired newborn infants taken under authority of Section 504, including pending investigation and other enforcement actions, with respect to "any program or activity receiving Federal financial assistance." *See* 29 U.S.C. § 794 and 29 U.S.C. § 706(14).

Dated: New York, New York
June 11, 1984

/s/ Charles L. Brieant
CHARLES L. BRIEANT
U.S. District Judge

## APPENDIX E

45 C.F.R. 84.55 and 45 C.F.R. Pt. 84, App. C, as added by 49 Fed. Reg. 1650 *et seq.* (1984), provides:

PART 84—[AMENDED]

The authority citation for Part 84 is as follows:

Authority: Sec. 504, Rehabilitation Act of 1973, Pub. L. 93-112, 87 Stat. 394 (29 U.S.C. 794974) [*sic*]; sec. 111(a), Rehabilitation Act Amendments of 1974, Pub. L. 93-516, 88 Stat. 1619 (29 U.S.C. 706); sec. 606, Education of the Handicapped Act (20 U.S.C. 1405), as amended by Pub. L. 94-142, 89 Stat. 795; sec. 321, Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970, 84 Stat. 182 (42 U.S.C. 4581), as amended; sec. 497, Drug Abuse Office and Treatment Act of 1972, 86 Stat. 78 (21 U.S.C. 1174), as amended.

For the reasons set forth in the preamble:

1. 45 CFR Part 84 is amended by inserting after § 84.54 the following new § 84.55:

§ 84.55 Procedures relating to health care for handicapped infants.

(a) *Infant Care Review Committees.* The Department encourages each recipient health care provider that provides health care services to infants in programs receiving Federal financial assistance to establish an Infant Care Review Committee (ICRC) to assist the provider in delivering health care and related services to infants and in complying with this part. The purpose of the committee is to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concern-

ing medically beneficial treatment in specific cases. While the Department recognizes the value of ICRC's in assuring appropriate medical care to infants, such committees are not required by this section. An ICRC should be composed of individuals representing a broad range of perspectives, and should include a practicing physician, a representative of a disability organization, a practicing nurse, and other individuals. A suggested model ICRC is set forth in paragraph (f) of this section.

(b) *Posting of informational notice.* (1) Each recipient health care provider that provides health care services to infants in programs or activities receiving Federal financial assistance shall post and keep posted in appropriate places an informational notice.

(2) The notice must be posted at location(s) where nurses and other medical professionals who are engaged in providing health care and related services to infants will see it. To the extent it does not impair accomplishment of the requirement that copies of the notice be posted where such personnel will see it, the notice need not be posted in area(s) where parents of infant patients will see it.

(3) Each health care provider for which the content of the following notice (identified as Notice A) is truthful may use Notice A. For the content of the notice to be truthful: (i) The provider must have a policy consistent with that stated in the notice; (ii) the provider must have a procedure for review of treatment deliberations and decisions to which the notice applies, such as (but not limited to) an Infant Care Review Committee; and (iii) the statements concerning the identity of callers and retaliation are truthful.

*Notice A:*

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

It is the policy of this hospital, consistent with Federal law, that, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify designated hospital contact point and telephone number] or

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

(4) Health care providers other than those described in paragraph (b)(3) of this section must post the following notice (identified as Notice B):

*Notice B:*

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Federal law prohibits discrimination on the basis of handicap. Under this law, nourishment and medi-

cally beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, applies to programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day: TDD capability.

The identity of callers will be held confidential. Federal regulations prohibit retaliation by this hospital against any person who provides information about possible violations.

(5) The notice may be no smaller than 5 by 7 inches, and the type size no smaller than that generally used for similar internal communications to staff. The recipient must insert the specified information on the notice it selects. Recipient hospitals in Washington, D.C. must list 863-0100 as the telephone number for HHS. No other alterations may be made to the notice. Copies of the notices may be obtained from the Department of Health and Human Services upon request, or the recipient may produce its own notices in conformance with the specified wording.

(c) *Responsibilities of recipient state child protective services agencies.* (1) Within 60 days of the effective date of this section, each recipient state child protective services agency shall establish and maintain in written form methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances

of unlawful medical neglect of handicapped infants. These methods of administration and procedures shall include:

(i) A requirement that health care providers report on a timely basis to the state agency circumstances which they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants;

(ii) A method by which the state agency can receive reports of suspected unlawful medical neglect of handicapped infants from health care providers, other individuals, and the Department on a timely basis;

(iii) Immediate review of reports of suspected unlawful medical neglect of handicapped infants and, where appropriate, on-site investigation of such reports;

(iv) Provision of child protective services to such medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the provision of necessary nourishment and medical treatment; and

(v) Timely notification to the responsible Department official of each report of suspected unlawful medical neglect involving the withholding, solely on the basis of present or anticipated physical or mental impairments, of treatment or nourishment from a handicapped infant who, in spite of such impairments, will medically benefit from the treatment or nourishment, the steps taken by the state agency to investigate such report, and the state agency's final disposition of such report.

(2) Whenever a hospital at which an infant who is the subject of a report of suspected unlawful medical neglect is being treated has an Infant Care Re-

view Committee (ICRC) the Department encourages the state child protective services agency to consult with the ICRC in carrying out the state agency's authorities under its state law and methods of administration. In developing its methods of administration and procedures, the Department encourages child protective services agencies to adopt guidelines for investigations similar to those of the Department regarding the involvement of ICRC's.

(The provisions of § 84.55(c) have been approved by the Office of Management and Budget pursuant to the Paperwork Reduction Act. The OMB No. is 0990-0114.)

(d) *Expedited access to records.* Access to pertinent records and facilities of a recipient pursuant to 45 CFR 80.6(c) (made applicable to this part by 45 CFR 84.61) shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

(e) *Expedited action to effect compliance.* The requirement of 45 CFR 80.8(d)(3) pertaining to notice to recipients prior to the initiation of action to effect compliance (made applicable to this part by 45 CFR 84.61) shall not apply when, in the judgment of the responsible Department official, immediate action to effect compliance is necessary to protect the life or health of a handicapped individual. In such cases the recipient will, as soon as practicable, be given oral or written notice of its failure to comply, of the action to be taken to effect compliance, and its continuing opportunity to comply voluntarily.

(f) *Model Infant Care Review Committee.* Recipient health care providers wishing to establish Infant Care Review Committees should consider adoption of

the following model. This model is advisory. Recipient health care providers are not required to establish a review committee or, if one is established, to adhere to this model. In seeking to determine compliance with this part, as it relates to health care for handicapped infants, by health care providers that have an ICRC established and operated substantially in accordance with this model, the Department will, to the extent possible, consult with the ICRC.

(1) *Establishment and purpose.* (i) The hospital establishes an Infant Care Review Committee (ICRC) or joins with one or more other hospitals to create a joint ICRC. The establishing document will state that the ICRC is for the purpose of facilitating the development and implementation of standards, policies and procedures designed to assure that, while respecting reasonable medical judgments, treatment and nourishment not be withheld, solely on the basis of present or anticipated physical or mental impairments, from handicapped infants who, in spite of such impairments, will benefit medically from the treatment or nourishment.

(ii) The activities of the ICRC will be guided by the following principles:

(A) The interpretative guidelines of the Department relating to the applicability of this part to health care for handicapped infants.

(B) As stated in the "Principles of Treatment of Disabled Infants" of the coalition of major medical and disability organizations, including the American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association, and others:

When medical care is clearly beneficial, it should always be provided. When appropriate medical care

is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

(C) As stated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

This (standard for providing medically beneficial treatment) is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to

undervalue the lives of handicapped infants; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

(iii) The ICRC will carry out its purposes by:

(A) Recommending institutional policies concerning the withholding or withdrawal of medical or surgical treatments to infants, including guidelines for ICRC action for specific categories of life-threatening conditions affecting infants;

(B) Providing advice in specific cases when decisions are being considered to withhold or withdraw from infant life-sustaining medical or surgical treatment; and

(C) Reviewing retrospectively on a regular basis infant medical records in situations in which life-sustaining medical or surgical treatment has been withheld or withdrawn.

(2) *Organization and staffing.* The ICRC will consist of at least 7 members and include the following:

(i) A practicing physician (e.g., a pediatrician, a neonatologist, or a pediatric surgeon),

(ii) A practicing nurse,

(iii) A hospital administrator,

(iv) A representative of the legal profession,

(v) A representative of a disability group, or a developmental disability expert,

(vi) A lay community member, and

(vii) A member of a facility's organized medical staff, who shall serve as chairperson.

In connection with review of specific cases, one member of the ICRC shall be designated to act as "special advocate" for the infant, as provided in par-

agraph (f)(3)(ii)(E) of the section. The hospital will provide staff support for the ICRC, including legal counsel. The ICRC will meet on a regular basis, or as required below in connection with review of specific cases. It shall adopt or recommend to the appropriate hospital official or body such administrative policies as terms of office and quorum requirements. The ICRC will recommend procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the ICRC and its availability on a 24-hour basis.

(3) *Operation of ICRC*—(i) *Prospective policy development.* (A) The ICRC will develop and recommend for adoption by the hospital institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. These will include guidelines for management of specific types of cases or diagnoses, for example, Down's syndrome and spina bifida, and procedures to be followed in such recurring circumstances as, for example, brain death and parental refusal to consent to life-saving treatment. The hospital, upon recommendation of the ICRC, may require attending physicians to notify the ICRC of the presence in the facility of an infant with a diagnosis specified by the ICRC, e.g., Down's syndrome and spina bifida.

(B) In recommending these policies and guidelines, the ICRC will consult with medical and other authorities on issues involving disabled individuals, e.g., neonatologists, pediatric surgeons, county and city agencies which provide services for the disabled, and disability advocacy organizations. It will also consult with appropriate committees of the medical staff, to ensure that the ICRC policies and guidelines build on

existing staff by-laws, rules and regulations concerning consultations and staff membership requirements. The ICRC will also inform and educate hospital staff on the policies and guidelines it develops.

(ii) *Review of specific cases.* In addition to regularly scheduled meetings, interim ICRC meetings will take place under specified circumstances to permit review of individual cases. The hospital will, to the extent possible, require in each case that life-sustaining treatment be continued, until the ICRC can review the case and provide advice.

(A) Interim ICRC meetings will be convened within 24 hours (or less if indicated) when there is disagreement between the family of an infant and the infant's physician as to the withholding or withdrawal of treatment, when a preliminary decision to withhold or withdraw life-sustaining treatment has been made in certain categories of cases identified by the ICRC, when there is disagreement between members of the hospital's medical and/or nursing staffs, or when otherwise appropriate.

(B) Such interim ICRC meetings will take place upon the request of any member of the ICRC or hospital staff or parent or guardian of the infant. The ICRC will have procedures to preserve the confidentiality of the identity of persons making such requests, and such persons shall be protected from reprisal. When appropriate, the ICRC or a designated member will inform the requesting individual of the ICRC's recommendation.

(C) The ICRC may provide for telephone and other forms of review when the timing and nature of the case, as identified in policies developed by the ICRC, make the convening of an interim meeting impracticable.

(D) Interim meetings will be open to the affected parties. The ICRC will ensure that the interests of the parents, the physician, and the child are fully considered; that family members have been fully informed of the patient's condition and prognosis; that they have been provided with a listing which describes the services furnished by parent support groups and public and private agencies in the geographic vicinity to infants with conditions such as that before the ICRC; and that the ICRC will facilitate their access to such services and groups.

(E) To ensure a comprehensive evaluation of all options and factors pertinent to the committee's deliberations, the chairperson will designate one member of the ICRC to act, in connection with that specific case, as special advocate for the infant. The special advocate will seek to ensure that all considerations in favor of the provision of life-sustaining treatment are fully evaluated and considered by the ICRC.

(F) In cases in which there is disagreement on treatment between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the family's wishes will be carried out, for as long as the family wishes, unless such treatment is medically contraindicated. When there is physician/family disagreement and the family refuses consent to life-sustaining treatment, and the ICRC, after due deliberation, agrees with the family, the ICRC will recommend that the treatment be withheld. When there is physician/family disagreement and the family refuses consent, but the ICRC disagrees with the family, the ICRC will recommend to the hospital board or appropriate official that the case be referred immediately to an appropriate court or child protective agency, and every effort shall be

made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition until such time as the court or agency renders a decision or takes other appropriate action. The ICRC will also follow this procedure in cases in which the family and physician agree that life-sustaining treatment should be withheld or withdrawn, but the ICRC disagrees.

(iii) *Retrospective record review.* The ICRC, at its regularly-scheduled meeting, will review all records involving withholding or termination of medical or surgical treatment to infants consistent with hospital policies developed by the ICRC, unless the case was previously before the ICRC pursuant to paragraph (f)(3)(ii) of this section. If the ICRC finds that a deviation was made from the institutional policies in a given case, it shall conduct a review and report the findings to appropriate hospital personnel for appropriate action.

(4) *Records.* The ICRC will maintain records of all of its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Such records will be kept in accordance with institutional policies on confidentiality of medical information. They will be made available to appropriate government agencies, or upon court order, or as otherwise required by law.

Amendment to Table of Contents

2. The table of contents to 45 CFR Part 84 is amended by striking the designation of "84.55-84.60 [Reserved]" and by inserting in lieu thereof, the following:

Sec.

84.55 Procedures relating to health care for handicapped infants.

84.56-84.60 [Reserved]

3. 45 CFR Part 84 is amended by inserting after Appendix B the following new appendix:

Appendix C—Guidelines Relating to Health Care for Handicapped Infants.

(a) *Interpretative guidelines relating to the applicability of this part to health care for handicapped infants.* The following are interpretative guidelines of the Department set forth here to assist recipients and the public in understanding the Department's interpretation of section 504 and the regulations contained in this part as applied to matters concerning health care for handicapped infants. These interpretative guidelines are illustrative; they do not independently establish rules of conduct.

(1) With respect to programs and activities receiving Federal financial assistance, health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

(2) Futile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant.

(3) In determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected.

(4) Section 504 and the provisions of this part are not applicable to parents (who are not recipients of Federal financial assistance). However, each recipient health care provider must in all aspects of its health care programs receiving Federal financial assistance provide health care and related services in a manner consistent with the requirements of section 504 and this part. Such aspects includes decisions on whether to report, as required by State law or otherwise, to the appropriate child protective services agency a suspected instance of medical neglect of a child, or to take other action to seek review or [*sic*] parental decisions to withhold consent for medically indicated treatment. Whenever parents make a decision to withhold consent for medically beneficial treatment or nourishment, such recipient providers may not, solely on the basis of the infant's present or anticipated future mental or physical impairments, fail to follow applicable procedures on reporting such incidents to the child protective services agency or to seek judicial review.

(5) The following are examples of applying these interpretative guidelines. These examples are stated in the context of decisions made by recipient health care providers. Were these decisions made by parents, the guideline stated in section (a)(4) would apply. These examples assume no facts or complications other than those stated. Because every case must be examined on its individual facts, these are merely illustrative examples to assist in understanding the framework for applying the nondiscrimination requirements of section 504 and this part.

(i) Withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome when the withholding is based

upon the anticipated future mental retardation of the infant and there are no medical contraindications to the surgery that would otherwise justify withholding the surgery would constitute a discriminatory act, violative of section 504.

(ii) Withholding of treatment for medically correctable physical anomalies in children born with spina bifida when such denial is based on anticipated mental impairment, paralysis or incontinence of the infant, rather than on reasonable medical judgments that treatment would be futile, too unlikely of success given complications in the particular case, or otherwise not of medical benefit to the infant, would constitute a discriminatory act, violative of section 504.

(iii) Withholding of medical treatment for an infant born with anencephaly, who will inevitably die within a short period of time, would not constitute a discriminatory act because the treatment would be futile and do no more than temporarily prolong the act of dying.

(iv) Withholding of certain potential treatments from a severely premature and low birth weight infant on the grounds of reasonable medical judgments concerning the improbability of success or risks of potential harm to the infant would not violate section 504.

(b) *Guidelines for HHS investigations relating to health care for handicapped infants.* The following are guidelines of the Department in conducting investigations relating to health care for handicapped infants. They are set forth here to assist recipients and the public in understanding applicable investigative procedures. These guidelines do not establish rules of conduct, create or affect legally enforceable

rights of any person, or modify existing rights, authorities or responsibilities pursuant to this part. These guidelines reflect the Department's recognition of the special circumstances presented in connection with complaints of suspected life-threatening noncompliance with this part involving health care for handicapped infants. These guidelines do not apply to other investigations pursuant to this part, or other civil rights statutes and rules. Deviations from these guidelines may occur when, in the judgment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant.

(1) Unless impracticable, whenever the Department receives a complaint of suspected life-threatening noncompliance with this part in connection with health care for a handicapped infant in a program or activity receiving Federal financial assistance, HHS will immediately conduct a preliminary inquiry into the matter by initiating telephone contact with the recipient hospital to obtain information relating to the condition and treatment of the infant who is the subject of the complaint. The preliminary inquiry, which may include additional contact with the complainant and a requirement that pertinent records be provided to the Department, will generally be completed within 24 hours (or sooner if indicated) after receipt of the complaint.

(2) Unless impracticable, whenever a recipient hospital has an Infant Care Review Committee, established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the Department will, as part of its preliminary inquiry, solicit the information available to, and the analysis and recommendations of, the ICRC. Unless, in the judg-

ment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant, prior to initiating an on-site investigation, the Department will await receipt of this information from the ICRC for 24 hours (or less if indicated) after receipt of the complaint. The Department may require a subsequent written report of the ICRC's findings, accompanied by pertinent records and documentation.

(3) On the basis of the information obtained during preliminary inquiry, including information provided by the hospital (including the hospital's ICRC, if any), information provided by the complainant, and all other information obtained, the Department will determine whether there is a need for an on-site investigation of the complaint. Whenever the Department determines that doubt remains that the recipient hospital or some other recipient is in compliance with this part or additional documentation is desired to substantiate a conclusion, the Department will initiate an on-site investigation or take some other appropriate action. Unless impracticable, prior to initiating an on-site investigation, the Department's medical consultant (referred to in paragraph 6) will contact the hospital's ICRC or appropriate medical personnel of the recipient hospital.

(4) In conducting on-site investigations, when a recipient hospital has an ICRC established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the investigation will begin with, or include at the earliest practicable time, a meeting with the ICRC or its designees. In all on-site investigations, the Department will make every effort to minimize any potential inconvenience or disruption, accommodate the schedules of health care profes-

sionals and avoid making medical records unavailable. The Department will also seek to coordinate its investigation with any related investigations by the state child protective services agency so as to minimize potential disruption.

(5) It is the policy of the Department to make no comment to the public or media regarding the substance of a pending preliminary inquiry or investigation.

(6) The Department will obtain the assistance of a qualified medical consultant to evaluate the medical information (including medical records) obtained in the course of a preliminary inquiry or investigation. The name, title and telephone number of the Department's medical consultant will be made available to the recipient hospital. The Department's medical consultant will, if appropriate, contact medical personnel of the recipient hospital in connection with the preliminary inquiry, investigation or medical consultant's evaluation. To the extent practicable, the medical consultant will be a specialist with respect to the condition of the infant who is the subject of the preliminary inquiry or investigation. The medical consultant may be an employee of the Department or another person who has agreed to serve, with or without compensation, in that capacity.

(7) The Department will advise the recipient hospital of its conclusions as soon as possible following the completion of a preliminary inquiry or investigation. Whenever final administrative findings following an investigation of a complaint of suspected life-threatening noncompliance cannot be made promptly, the Department will seek to notify the recipient and the complainant of the Department's decision on whether the matter will be immediately referred to the Department of Justice pursuant to 45 CFR 80.8.

(8) Except as necessary to determine or effect compliance, the Department will (i) in conducting preliminary inquiries and investigations, permit information provided by the recipient hospital to the Department to be furnished without names or other identifying information relating to the infant and the infant's family; and (ii) to the extent permitted by law, safeguard the confidentiality of information obtained.

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